

## **Amyotrophic Lateral Sclerosis: Part 2 of 2**

By Ruth Werner, LMP, NCTMB

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*Editor's note:* Part 1 of this article appeared in the July 2005 issue. To read part 1 online, visit [www.massagetoday.com/archives/2005/07/15.html](http://www.massagetoday.com/archives/2005/07/15.html).

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Dear Readers:

I love my job! I put out the call for you to share your experiences with all *Massage Today* readers about working with clients who have ALS.

The response was overwhelming. I received letters that touched me to the core. What does this tell us? That massage therapists are active and involved with this population, and they are generous and invested in getting the word out about the value of their work.

I have compiled a collection of some of the responses you sent. If you wrote to me and I didn't use your piece, it's just because space is limited - please don't feel slighted. I will post all the responses I received (from people who gave permission to use them) on my Web site ([www.ruthwerner.com](http://www.ruthwerner.com)). Click on "*Massage Today* Replies" to read them.

Before we look at a few of the responses from massage therapists in the field, here is a brief overview of amyotrophic lateral sclerosis, also known as Lou Gehrig's disease.

Amyotrophic lateral sclerosis (ALS) is a chronic, progressive central nervous system disease involving the atrophy and eventual destruction of upper and lower motor neurons. This leads to muscular atrophy and ultimately to paralysis. It is considered an idiopathic disease, but as research reveals new information about neurotransmitter dysfunction and synaptic damage, we might eventually find ways to interrupt this process. For the time being, however, ALS has a poor prognosis: Most patients die within two to 10 years of

diagnosis, usually from respiratory failure.

ALS often starts in the extremities and progresses toward the core. As the motor nerves degenerate, symptoms include fasciculations (uncontrolled shaking) and spasm. Although the disease does not attack sensory neurons, ALS can be painful as the structure of the body collapses. This disease does not affect cognitive function at all.

Currently, about 20,000 people in the U.S. live with ALS, and based on the amount of feedback I received, it seems a lot of them are receiving massage! The techniques described varied greatly. Some therapists have found that deep, specific work helped to improve and maintain function. Others have found their clients especially loved being stretched and mobilized. As clients neared death, of course, the bodywork they received became gentler. One recurring theme: Some ALS clients can't speak clearly, or at all. This makes it especially important to be sensitive to nonverbal communications about what feels good and what doesn't.

With that said, read on and benefit from what your colleagues have learned:

My brother-in-law, Randy, had the more aggressive, bulbar form of the disease, and lasted only two years and eight months from the onset of symptoms. He was an ideal athletic specimen when he was first diagnosed, and by the time he passed, he was skin and bones trapped in an unresponsive body.

From the beginning, Randy told us the massage, which was primarily Swedish, was a great relief and helped reduce fasciculations and spasticity. As the symptoms progressed, I took a different approach and incorporated a more vigorous massage with stretching and craniosacral therapy, to help alleviate the soreness created by immobility.

In the advanced stages, when there was little muscle tissue left, it was very important that all the work was focused and gentle, so as to not alter the spinal column, which had collapsed in on it. A sudden movement could cause him excruciating pain, and because he lost his ability to speak after the first year, it was essential that I watch his facial expressions for response. At the end, he was in such agony that nothing offered sustainable relief, but he responded to gentle touch along with hand and foot massage.

My experience with Randy was truly life-altering. I felt honored to have been able to provide any relief that I may have. For those considering taking on this task, I suggest that you learn about the disease, and be prepared to witness incredible pain and suffering. The benefits to the client, however, are

greatly worth the effort.

*Cassandra Curley, LMT*

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What upsets me about articles such as yours is ... never does anybody even mention the emotional component of this disease. I think stress may well be the major component and it is always ignored (in all my wisdom ... having dealt with only my mother's "case" - and this was prior to massage therapy training). Every article I've read since continues to be silent on the emotional aspects of this condition. I continue to be baffled.

My mother lived with a seriously emotionally abusive (and later diagnosed as emotionally disturbed) husband (my father) to the very end. EVERYbody in my family thinks this abuse was THE cause of her illnesses. The doctors at Hopkins (to my knowledge) NEVER asked one word about her emotions ... NEVER.

*Elaine C. Ashton*

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I'm presently treating a dear friend/patient who I was treating well before his recent diagnosis with ALS. The work he requests is very deep, digital, focused work on his forearms, and legs - areas that are progressively getting weaker and ache deeply. I don't ever give him a "full-body Swedish."

He has one of those microphones so I can understand him, but both his breathing and his speech are progressively deteriorating.

*Charlotte Michael Versagi*

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I am a CMT who has been doing hospice massage on ALS clients for over a year on a weekly basis. For us, it is definitely a win-win situation. My client can no longer move or talk, but her eyes sure light up when I enter the room. I spend most of my time working on the scalp, hands and feet. I use gentle compression on arms and legs. Her body is so atrophied; there is no muscle tissue to work. In the reclining position, I place one hand under the small of her back and the other hand gently on her abdomen and 'just be' for about five minutes. Another technique I have learned to do with her that she obviously enjoys is this: Again in the reclining chair, bring the heels up to the buttocks. Put one hand between the knees so they are not incurring friction and place the other hand on top of the knees. Gently and slowly rock the knees back

and forth as far as possible several times. This movement always invokes a beautiful smile on my client's face. The nurturing and rocking motion is so very soothing and it has to be good for the lower back and hips.

To know I can help someone in such a horrible situation to feel pleasure is most satisfying to me.

*Jill Nixon, CMT*

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Four years ago, my stepsister, Robin, was diagnosed with ALS at age 48.

The first thing that was affected was her speech. Go figure. Robin had always been a motor mouth, talking up a storm to anyone who would listen, calling everyone "dee-ah," using an exaggerated Maine accent.

On a visit to Robin soon after her diagnosis, I asked if I could do some massage work on her. (As teenagers, she always loved me to pluck her eyebrows; thinking back, I think she just loved being touched!) She was excited about the prospect of getting massage and I ended up spending a lot of the time that day working on her neck and jaw. After that session, her speech was clearer for many hours. We were all very excited about this and I taught her live-in family how to accomplish the same results. This worked well for a few weeks. She felt it also helped her with swallowing.

Throughout her illness, I was able to visit weekly and do full-body massage. Robin was determined to get on my table every time. Even when she was in a wheelchair full time, she wanted to be on the table and she wanted the full treatment! I would specifically work on areas that had been in spasm that week, and we also worked on range of motion of her extremities and using that strong mind of hers to try to send the message of movement through to her limbs.

Robin had made the decision to have no intervention in the progression of ALS. She was determined to stay at home and to die at home. She wanted no feeding tube or breathing apparatus. I taught her son and primary caregiver Johnny massage techniques to use on her when I was not there, and he was religious about doing range of motion and releasing her cramping manually.

When Robin had decided that she had had enough, it had been just one-and-a-half years since diagnosis. At that point she had spent a few days not getting out of bed. She asked the family to the house and she asked me specifically to give her one last full massage session. As I worked on her, family members

filtered in and out of the room, visiting. Robin was making her usual groans of delight about the massage she was receiving. Robin died peacefully two days later with her family around her.

I have now collected a group of "Robin's Angels" - massage therapists who go into the homes of people with ALS to massage them. There is no greater reward in this work than to be able to help victims of ALS in this way.

*Debra Roof, LMT*

Once again, I am filled with awe and gratitude at the generosity of people in our profession. Aren't you proud to be a massage therapist?

For next time: Fall is upon us. It might be time for an update on the flu, especially on the latest developments about avian flu. This is not to be a fear-mongering alarmist, but simply to help us arm ourselves with the best possible protection: information. If you have other thoughts about what you'd like to see here, let me know: What's on your table?

Many blessings,

*Ruth Werner*

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Click [here](#) for more information about Ruth Werner, LMP, NCTMB.



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