

Yoga Therapy's Role in Long-term Care: Broadening Our Approach to Neuromuscular Conditions

© By *Nathalie de Meyenburg*

A person with a smiling face and a rather quizzical expression watches as you take off your coat, disengage your hands from a pair of gloves, and introduce yourself. The person is leaning heavily on a cane, body at an awkward angle, yet a hand is extended in greeting. Two hands touch, and a relationship begins.

Seeing the Whole Person

How do you perceive your role as a yoga therapist? From the moment you first meet a client (or perhaps even earlier, during a preliminary phone conversation) you are likely to be engaged in a longterm relationship. Therapists and healthcare providers may see their role as finite; their influence limited to their area of specialization and focused on a specific condition or disease; their time spent with a client or patient defined by minutes, hours, perhaps a few weeks or months. It is all too easy to compartmentalize the future as a clearly defined goal, thereby oversimplifying the focus of one's time spent with a client. We risk losing sight of the whole picture, defining a client by a specific condition or disease rather than as a person on a continuum of life experiences: physical challenges, thoughts and emotions, relationships, a spiritual path. Those of us with the privilege of being in a position to help others as a therapist, healthcare provider, or caregiver should endeavor to see the person, not merely the disease or its symptoms.

Truly seeing a person is much like trying to focus a camera: you first have a blurred image that you then attempt to bring into focus. This initial focus is often too narrow, excluding the background and surroundings; you must soften the focus and draw back to create a balanced picture. Similarly, practitioners and clients alike will benefit from a softer, more broadly focused approach. Rather than viewing their clients as clinical cases to be solved, yoga therapists have the opportunity to apply their unique outlook and knowledge base to act as a guide—and a support—on an extended journey. This may mean relinquishing the notion of setting a fixed, preset course—a protocol—with a predetermined destination.

Support vs. Protocol

In my experience, it would be difficult to overemphasize the importance of support versus protocol in long-term care. Although necessary within today's health system, clinical assessment and terminology tend to depersonalize our attitudes and outlook when working with special groups. This is evident in attempts to create a protocol based on yoga therapy studies: we may skim or condense outcomes in an effort to find conclusive results, yielding static, limited "recipes" for particular conditions. Given that many studies are of short duration either due to funding constraints or for practicality, the outcome can hardly be expected to reflect the extended spectrum of care needed for long-term conditions, disability, disease, or to be conclusive with

respect to lifelong neurological, neuromuscular, or movement disorders such as multiple sclerosis (MS) or Parkinson's disease. The result? People become numbers and percentages, yet little insight is gained into the overarching potential of a dynamic, personalized therapeutic modality such as yoga therapy.

Yoga therapy is uniquely suited as an adjunct form of support and long-term therapy for neurological, neuromuscular, and movement disorders due to its inherent potential for focusing less on a specific symptom or condition than on the overall effect on the person. Studies reflect yoga and yoga therapy's effectiveness in managing pain, fatigue, depression, and in improving gait, balance, and overall quality of life for those with MS and other neurological conditions.¹⁻³ Although these clinical results are positive steps toward the acceptance of yoga therapy into the current medical system, it is important not to lose sight of the fact that yoga itself has been a form of self-care for several thousand years. Quality of life is bound to improve when a patient or client is provided with a means to

- develop awareness (thereby damping down stress responses and anxiety or preventing a fall due to lack of attention).
- focus the mind and thought processes (enabling one to grasp and turn a doorknob or move a reluctant leg).
- ease pain, ameliorate depression, and increase physical ability.

Case in Point: MS

Neurological and neuromuscular disorders present long-term challenges that surpass the reach of mere “therapeutic intervention.” For example, MS is a complex, multifaceted neurodegenerative disease with an unpredictable progression. There is no known cure. Once diagnosed, it is likely that the person’s life will be marked by varying phases of progression, plateaus, and relapses. MS presents a host of symptoms that are too frequently the sole focus of healthcare providers. Symptoms are varied and unpredictable, ranging from imperceptible (benign MS) to profound (locked-in syndrome), and may include cognitive impairment, gait disturbances, vision disturbances, chronic pain, muscular weakness, joint contracture and muscle spasticity, abnormal sensations (paresthesias), and depression. Consequently, MS can be daunting to work with if one forgets that a person is not a spastic leg, a neurogenic bladder, or an ataxic gait: rather, they are a human being.

Multiple sclerosis translates literally as “many scars,” a clinical reference to the damage done by demyelination of the nerves (myelin is a protective sheath surrounding nerves), yet its allusion to scarring is also appropriate in describing the effect on people’s lives if they lack physical, emotional, and spiritual support. “I don’t want to stop being who I am” is a phrase I have heard more than once while working with those who have MS, reflecting the frustration of trying to keep up with the pace of the modern world, work, and frequently the personal stress of juggling a family and well-intentioned friends. The simplest effort, be it mental or physical, can become a huge challenge. In my experience,

In my experience, yoga therapy can help diffuse the effects of MS, both physically and mentally, especially when approached in a moderate, straightforward manner, avoiding the unnecessary complications and distractions of props. In many cases, it is not possible to use props at all due to severe spasticity or unilateral weakness (left-sided hemiparesis is common in MS). Preconceptions of ability or disability can also be an impediment; Assuming every person cannot stand—or needs a chair—just because he or she arrives in a wheelchair will not serve the client in good stead. Simplicity is key, with an eye to improving or sustaining day-to-day wellbeing. The trajectory of a yoga therapy program for a neurological condition or movement disorder is not likely to follow an upward, 45-degree line, the hallmark Of “positive” clinical interventions. A client’s repeated acknowledgment of improved quality of life, sense of wellbeing, and feeling of autonomy gained from learning and implementing a form of self-care are far more durable testimony to the benefits of yoga therapy.

As a yoga therapist working with those with neurological conditions and neuromuscular disorders, I provide one-to-one therapy with clients in their homes, sometimes for many years. As a result, they receive long-term, practical support from a therapist who knows them from a multidimensional perspective, rather than intermittent, short-term courses of therapy. When we see clients regularly over the course of several years, we can appreciate and learn from the changes that take place, both from their perspective and from our own. At the outset, both practitioner and client wish for leaps and bounds, whereas the changes are likely to be subtle and more finite. Recently, during a pause in a particularly intense session focused on using a weak leg more supportively

while walking with a cane, a client with MS made the connection that raising her arms on an inhale while stepping forward was a diminutive version of Warrior I, something she had been able to do years ago and could still feel within her body. That is our role as a therapist: to bring awareness to the moment, acknowledging the past and stepping only one foot at a time into the future.

Resilience

As I speak with fellow yoga therapists, listen to perspectives and opinions, or read the growing body of literature on approaches to yoga therapy, one element is often missing: a recognition of the resilience of the human spirit, something that is not crushed by trauma, injury, or chronic illness. Not recognizing the inherent strength, spirit, and willpower in each of us negates a fundamental aspect of being human, and of being alive. In the midst of grief, strife, and utter deprivation, humans tend to be at their strongest and most determined. If our outlook as therapists is obscured by a dark lens and by the conviction that each client is in some way broken, bruised, and too sensitive for a frank, open conversation and the long journey ahead, we deprive them of the opportunity to grasp our hand and pull themselves forward. Mahatma Gandhi spoke eloquently to this aspect of the human soul when he said, “Strength does not come from physical capacity. It comes from an indomitable will.”⁴ Strength resides in gentleness, perseverance, and endurance. Use these as your tools, but also recognize them in your clients.

As a yoga therapist, caregiver, healthcare provider, we may be with our client through good times; very difficult and complicated times; and yes, death. One must be able to find joy in the sadness of watching someone with early-onset Parkinson’s change from a well-spoken, outgoing person to a shuffling, mute, and distant person;

of seeing someone with MS who is active, raising a family, and engaged in their profession eventually apply for disability, stop working, and get divorced due to marital strain; or of guiding someone with ALS to breathe through the last few weeks of their life. Joy? Impossible, surely! And yet, the years spent helping them remain upright and walking on their own; the astonished doctor who could not believe that yes, indeed, their patient can still get on the floor and back up without a chair or prop; the breathing exercises to cope with the relentless compression of an “MS hug” or to give a voice to the faintly whispered communication during later-stage Parkinson’s are a form of bitter sweet joy—lessons gained from perception, introspection, and the passage of time.

Looking Ahead

For yoga therapists brushing arms with—or integrating into—the modern healthcare system, there is a potential danger of over-sharpening one’s viewpoint to the point where we practically exclude the person in an effort to manage the disease or fix a perceived problem. How do we put into practice the concept of guided longterm care/therapy while maintaining an approach that prioritizes the person? Strive to find a middle ground, then continue adjusting the focus by questioning, observing, and learning. Modern medical science uses empirical evidence, a source of knowledge acquired by observation or experimentation as a basis for a hypothesis and as the means to prove the hypothesis’s validity or lack thereof. Yoga could be said to be one of the oldest and most rigorously tested sources of self-care and self-knowledge, a deep and comprehensive source of experience that yoga therapists have at their fingertips. As in any healing tradition—modern, ancient, Eastern, or Western—the efficacy, benefits, and impact will rest in the hands of the

practitioners and their skill, empathy, and willingness to diminish ego in the interest of caring for others, not only in body, but in spirit.

YTT

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