The Progression of Oncology Massage

Difficult Lessons Learned

BY GAYLE MACDONALD

When I started working in the field of oncology massage in 1994, there was almost nothing in the massage literature to guide me. I learned by trial and error. Because I am an inherently gentle bodyworker, there weren't many errors, but there were some. Even though it isn't my usual style—I prefer the positive and inspirational—I am going to try to motivate practitioners through the use of stories about mistakes made by me and others when working with cancer survivors. Of course, I hate mistakes, but they have been some of my best teachers and served me in ways that my successes could not. These miscalculations borne of progress were difficult to bear, but they have been beneficial. For that I am grateful.

The first and perhaps most horrendous mistake occurred in 2000 when I had just begun teaching continuing education classes for private practitioners after six years of being in the hospital environment. One of the clients who attended the clinic that weekend developed lymphedema because the therapist massaged too forcefully around the scapula in the treated quadrant. The swelling was evident within hours, much to the client's displeasure. Even though she played a part in the process by badgering the therapist for more pressure, the responsibility ultimately lay with us as professionals. Suffice it to say I woke up quickly to the fact that I needed to know more about how to adapt massage for those at risk for lymphedema. I learned fast and made immediate changes in my curriculum.

This was my initiation into the complexity of working with patients who had finished treatment and felt no adjustments were necessary for their sessions. To find solace in what happened, I had to translate it into something meaningful. I had to see the way in which it would serve the greater good by speeding up the learning curve for everyone I taught or influenced. Because of that one incident, I surmised that thousands of therapists are now wiser about how to adjust their techniques for the person at risk for lymphedema and many, many thousands of clients have had safer massages because of it.

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THE NEXT STEP

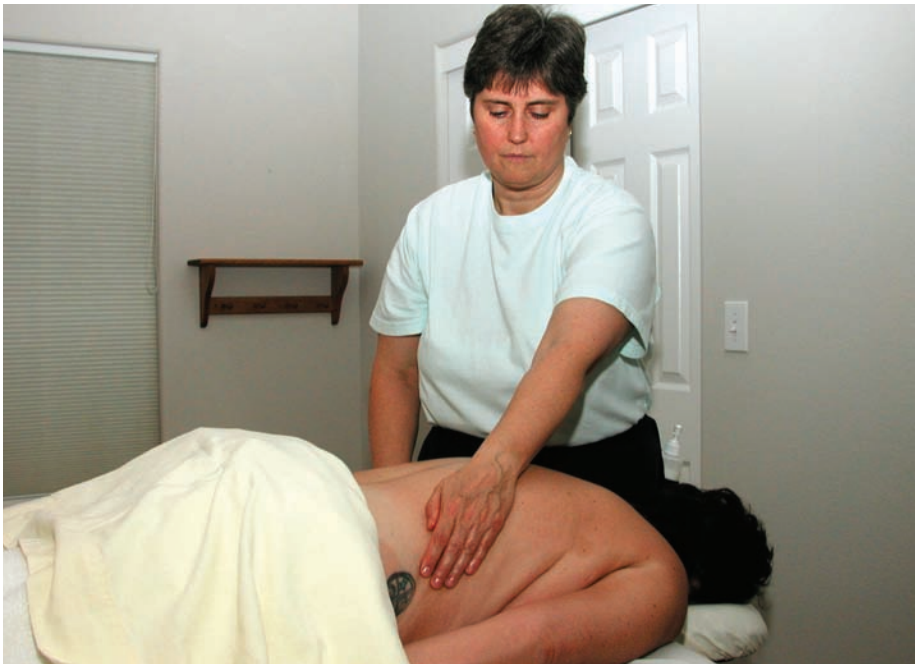
Many years ago, one of the challenges for those teaching oncology massage was to eliminate the myth that "massage is contraindicated because it will spread cancer." The metastasis hurdle has mostly been cleared, thanks to knowledge gained from genetic and biochemical research. There is another goal I would now like to work toward—basic training for all massage students in oncology massage so that the real issues are understood. Cancer patients literally entrust themselves to our hands. I want their trust to be warranted. They are often vulnerable and need therapists who can meet them where they are—whether it is being at risk for lymphedema, or with fears about being touched, or in pain.

This article won't be a how-to that gives clinical instruction. All of that is available in other places. Instead, this will be a why-to article—why all massage students need to be trained at a basic level in their core curriculum to work with those affected by cancer treatment. Please note that throughout this article I use the language *people affected by cancer treatment* rather than *people living with cancer*. It isn't just clients in treatment who have side effects: many people, although in remission and no longer in treatment, are still affected by side effects from the interventions.

The stories here include outcomes that could mostly have been prevented with the right adjustments. My fear in taking the scared straight approach is that I'll sound like the Irish mother who admonishes her children to behave or the boogeyman will come take them away. We've already used the boogeyman approach with the metastasis issue. It isn't an effective solution. However, occasionally, there are times when it is appropriate to say, "Don't do that, someone will get hurt!"

LEARNING THROUGH STORIES

A couple of months after finishing treatment for breast cancer, "Marion" went for a massage. She was booked with a practitioner who didn't know how to work with someone affected by cancer treatment. The therapist, lacking in confidence, even made a face in Marion's presence that showed her discomfort. She told Marion that she didn't think she could massage her



Author Gayle MacDonald, above, has educated more than 2,000 practitioners on the basics of massage for clients affected by cancer treatment. *Photo courtesy of Gayle MacDonald.*

and left the room to confer with her supervisor. The supervisor affirmed to the practitioner that she could give the massage. To say the least, the session was completely dissatisfying and Marion stayed away from further massages for more than a year.

The sharing of stories, such as Marion's, is one of a teacher's most effective tools. Long after students have been given principles or guidelines, they will remember stories. In the last 11 years, I've taught approximately 2,000 massage therapists the basics of adapting massage for people affected by cancer treatment and taught another few hundred practitioners how to work with oncology patients in the hospital. These therapists have given more than a few thousand massages. Because of this, I have a huge reservoir of anecdotes that have been related to me by therapists and clients. These anecdotes will have more impact than me scrawling on in clinical mode about white blood cell suppression due to chemotherapy or the potential for vital organ damage from radiation. Each story that follows represents another 100 such anecdotes. They are not isolated, one-off occurrences. From these growing pains, we learn and are served both as therapists and as a massage community.

Run over by a truck. One of the largest group of anecdotes here fits under the heading "I felt as if I had been run over by a truck." In these stories, the clients received massage that was too vigorous. The typical reactions are flu-like symptoms, fatigue, or pain that usually lasts for three days. Both clients and therapists have told me such stories. Neither realized that although a deeper pressure feels comfortable at the time, later in the evening or the next day, the recipient might not feel well.

Willie, to my knowledge, has been our only Oregon Health and Science University patient who received a massage that was too vigorous, resulting in pain. He had been hospitalized for a bone marrow transplant. His nurse looked at his blood counts, which were all in the normal range and approved him to have "whatever he wants." Off to the side, I told the therapist that she still needed to decrease the amount of pressure, which she did. However, Willie awoke several times that night in pain, which he attributed to the massage. For the remaining time in the hospital, he turned down all offers of massage.

A bodyworker from a class in Oregon, newly graduated from massage school, had twice massaged a man who was being treated with chemo for pancreatic cancer. Prior to the cancer diagnosis, he had a lower back problem, which was his reason for seeking massage. The back problem had nothing to do with the cancer, so the therapist assumed it would be OK to apply deep pressure to it. After both sessions, the client felt horrible the next day. What the therapist didn't understand is that the side effects from chemotherapy affect the entire body, not just the area that has cancer.

Prior to her cancer diagnosis, "Diane" from Phoenix, Arizona, received weekly massages. Initially, when she was diagnosed with cancer, there was only shock. Just trying to put one foot in front of the other was more than she could do on some days. Diane was bombarded with doctor visits, tests, more tests, and procedures. Eventually, the only choice left was a bilateral mastectomy, after which, the doctors had difficulty controlling her pain.

During that time, massage was the last thing on Diane's mind, but once the pain was under control and life started to settle down, she started thinking about massage again. She hadn't been to her usual massage place for awhile and had no regular therapist. Diane told the therapist she was assigned to that she had had recent surgery and so

Quality client/therapist communication is crucial when doing oncology massage. *Photo courtesy of Gayle MacDonald.*

he got her an extra pillow to lie on. "I thought that would be enough and that if I just endured the pain of lying on my stomach, the massage would relax me and it would get better. The pain of lying on my stomach was just too much. Normally when a massage gets near the end, I think, 'Oh no, don't let it be over yet.' This time I couldn't get off that table fast enough," she says. "In defense of the therapist, I probably should have been a little more forceful when the pain started. I'm pretty sure he was new and had no experience in the area of 'massage after surgery.' While I've always enjoyed deep-tissue massage, that probably won't be the best for me for awhile, if ever."

A Colorado client had a lot of scarring after a post-op IV leaked into the tissues on the top of his hand. He booked a massage appointment because he wasn't able to bend his fingers and thought massage would help. The first time, the therapist massaged the area using moderate pressure. At the client's insistence, she worked a little deeper the next time. The third session, despite her better judgment, she massaged still deeper. By the next morning, his arm was so swollen above the elbow that he had to go to the emergency department for antibiotics.

As promised, this article is not meant to clinically analyze what went wrong in any of the above situations. Its aim is, through the use of anecdotes, to spur us as individuals and as a collective, into examining whether massage therapists need more basic training in order to work with the legions of cancer survivors who seek our services in every possible venue.

Of course, I could also include anecdotes of clients with chemo-induced neuropathy who've had foot massage or reflexology that caused pain for days and even weeks, clients who felt retraumatized from being handled too roughly by the bodyworker, or clients who have vomited at the end of massages because the level of vigor was too demanding. But I would like to use much of the remaining space for another category of client that is, to me, the most complex of all of those who have been through cancer treatment—the person at risk for lymphedema. Massaging people at risk for lymphedema is especially fraught with the potential for unwanted outcomes.

I assumed they knew. Lymphedema is an abnormal accumulation of water and proteins, mainly in subcutaneous tissues. Many people who have been through cancer treatment are at risk for it due to lymph node removal and/or radiation to the clusters of nodes in the neck, axilla, and groin. Unfortunately, there are too many accounts of lymphedema that

have been caused or exacerbated by massage that was too vigorous. Clients at risk for lymphedema are complicated to work with because it is an especially capricious condition that carries with it a lifetime of risk. However, with a few adjustments, these incidences are preventable.

A client from Amherst, Massachusetts, called her massage therapist in a state of panic to say that she had received a short chair massage at a fundraising event for cancer research and that she was worried the practitioner had used too much pressure in the area at risk for lymphedema. "I thought the therapists would know what they were doing since it was an event for cancer patients. When I got home, I started to worry that my lymphedema would get worse because she used so much pressure." Happily, this client's condition didn't worsen, but she was frightened as a result of the overly vigorous session and her trust in massage therapy was eroded. Many other clients aren't as fortunate as the above client.

"Linda," a massage therapist and cancer survivor from Fairfax, Virginia, developed lymphedema after breast cancer treatment, which included a mastectomy on the left side, with 12 nodes removed and a reduction on the right with eight nodes removed. She also had a TRAM flap reconstruction at the time of the mastectomy. One year later, she developed lymphedema on the left side which was treated with complex decongestive therapy. Linda has worn a compression sleeve for the last six years to help control the condition.

Several months after completing treatment for lymphedema, Linda's children gave her a gift certificate to a local spa. Her arm was stable and she felt it would be OK to use the gift certificate for a stone massage. Upon arriving at the spa, Linda filled out the usual intake form, noting that she had lymphedema. When she met the therapist, Linda mentioned again that she had lymphedema. The therapist didn't question her about it, so Linda assumed that he understood the condition.

When the therapist started to use the stones, Linda thought they were a bit too hot. However, never having had this type of session before, she thought that this was the way it was supposed to be and that the therapist knew what he was doing. At one point, he placed hot stones in her hands and told Linda to hold them. While holding the stones, Linda kept thinking about the lymphedema therapist telling her to avoid heat in the treated quadrant. She considered saying something but didn't because "he's the professional and knows what he's doing."

Linda was wrong. The next morning, her left arm was more swollen than it had been during the initial lymphedema episode. To get the swelling under control, she performed self-lymph drainage several times a day as well as "wrapping" her arm. After about a week, Linda's arm had reduced back to the point where she could once again wear a compression sleeve.

"Judy," another breast cancer survivor, nurse, and oncology massage specialist from Roseville, California, was rediagnosed with another primary breast cancer. Hoping to use massage in preparation for her upcoming surgical procedure, she scheduled an oncology massage from someone who was recommended to her. "I was so looking forward to being nurtured," she says. "I was sure it would help prepare me for my surgery and radiation therapy."

Before the massage began, the therapist stood beside the table and asked Judy several questions. "I thought it quite unusual that she didn't have me complete a health history. I volunteered that I was a breast cancer survivor and that I had had a lumpectomy with removal of a few nodes, radiation therapy, and

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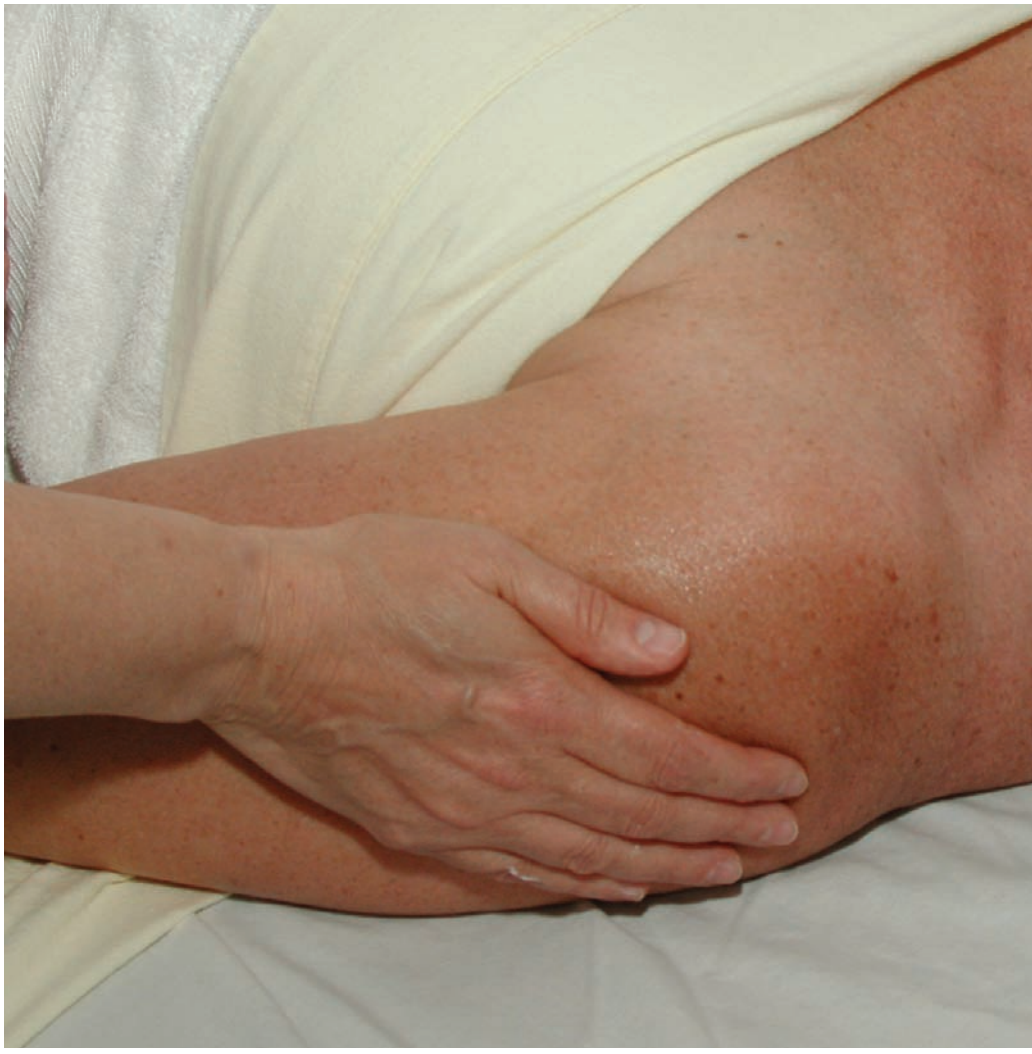
that I was at risk for lymphedema. We talked for about five minutes and then she asked me to get on the table, that she would 'be able to fix me up.'"

Judy was so anxious to receive a massage that she was not paying attention to what the therapist was saying or doing. The first missed clue was the amount of pressure the therapist used; it was way too much pressure for a cancer survivor, especially someone at risk for lymphedema. Judy thought maybe the pressure would get better. Not until the therapist began working on the arm at risk for lymphedema with a lot of pressure, including the axilla, did she really began to think, "This therapist doesn't know what she is doing." By the end of the massage, Judy had begun to feel slightly nauseated and by the next day, her affected arm was swollen with early stage lymphedema. "I was upset with myself that I did not speak up. The day after, I experienced flu-like symptoms that lasted almost up to the day of surgery."

After that experience, Judy was too afraid to allow anyone to touch her body, so she started gentle swimming to treat the lymphedema. "I swam every day prior to surgery to help with the lymphedema. I was as ready for surgery as I could be, but not in the way that I had wished."

It wasn't until after she completed her treatment that Judy recognized how angry she was with the therapist who caused the lymphedema. "How am I going to learn to trust another therapist? How come she didn't know about the dangers of using too much pressure? Why didn't she know the proper protocol for working with cancer survivors at risk for lymphedema? Why didn't she conduct a health history?"

"And, I was upset with myself for not speaking up," Judy laments. It was 18 months before she had enough confidence to receive another massage,



With 12 million cancer survivors in the United States, all massage therapists will need to know how to meet the needs of clients affected by cancer treatment. *Photo courtesy of Gayle MacDonald.*

and then only with a very trusted colleague. She knows now that her lesson is to empower others to speak up. While it is true that clients have a responsibility to speak up about their care, therapists must realize that they are responsible for holding the power differential of the therapist-client relationship as a sacred trust.

ONCOLOGY MASSAGE EDUCATION TODAY

Today, oncology massage education is in the place I had hoped for and in the place I most feared. Most schools no longer teach the long-held belief that massage will cause cancer to metastasize. That is a step forward. But schools are giving diverse instruction. Some teach to "check with the client's doctor." Doctors, however, aren't usually familiar with our work so they can't contribute from an informed basis. Other schools tell students it is OK to massage people affected by cancer, but to wait until they are trained. I like that message. Regrettably, many schools fail to take the next step—the provision of basic training. A few schools now include hours of

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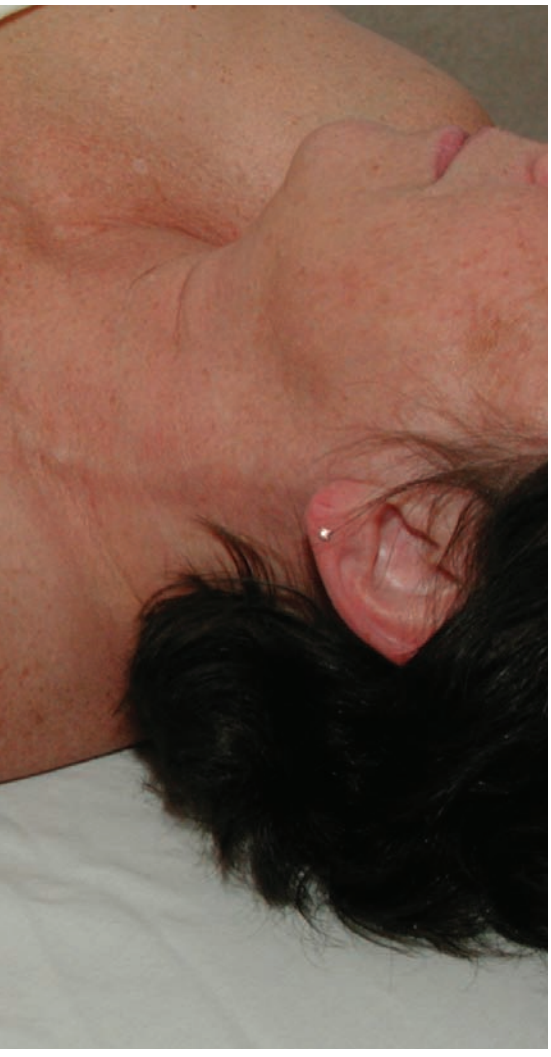

instruction and clinical experience about working with cancer patients. This is movement in the right direction.

What I also see taking place, and it is what I feared would happen, schools and therapists have discovered that massage is no longer seen as an activity that will trigger metastasis, but they don't realize that this is only one part of the message. The other part is that working with this population requires adequate training. Metastasis has never been the real issue. The actual problems stem from the side effects of treatment—surgery, chemo, and radiation. Besides the risk for lymphedema or triggering pain, people who have been through cancer treatment can have body image issues, decrease in bone health, incisional pain, long-term effects on vital organs, and unconscious trauma, just to name a few challenges.

There are no statistics on how many therapists have received fundamental training to work with oncology clients. Perhaps a quarter of one percent of massage therapists specialize in oncology massage. My guess is that only 10–20 percent of therapists have had bare-bones training in this area. However, all therapists will encounter clients who have been through cancer treatment—yes, all therapists. It is impossible to avoid them. According to the National Cancer Institute, there are 12 million cancer survivors in the United States. More than one in three women and nearly one in two men will be diagnosed with cancer at some point. Survivors are left with a variety of side effects years after treatment, which means that therapists will encounter them in their fitness center practice, spa, chiropractic office, at corporate massage events, and in private practice.

Ideally, clients and therapists will be partners in the therapeutic process. However, the greatest burden for the client's safety and well-being still lies with the massage practitioners, as well as those who train them, regulate the schools, and provide guidance to massage educators.

There is a collective question that arises from the stories in this article and the hundreds and hundreds of miscalculations that they represent: How can we best care for people affected by cancer? Are massage schools and therapists prepared well enough to meet their needs? Should the basic training for all massage students entail knowledge and experience with cancer clients? While it is true that a few mistakes occur despite a therapist's years of experience and knowledge, negative repercussions are mostly due to a lack of training and supervised experience. Mine surely were.

A number of groups need to sit around the table and try to address this issue: massage school owners, professional associations such as the Society for Oncology Massage, and perhaps groups such as the Oncology Nurses' Association and the National Lymphedema Network. I am completely aware that curriculum changes are a major undertaking for massage schools, but change at the grassroots level is the only way to provide a safer atmosphere for people affected by cancer treatment. Thanks to the progression of the work, so much is now known about the potential benefits and cautions of massaging these clients that practitioners don't need to work in the dark or be forced to reinvent the wheel.

Treatment for cancer is a draining and arduous process. It is my dream that all who have been through this experience can lie down on a massage therapist's table and relax, leave their vigilance at the door, wallow in the sensations of comfort, work gently toward improving their health, and become whole again in the presence of therapists who embrace the body, mind, and spirit exactly the way it is. **m&b**

Gayle MacDonald has been involved with oncology massage since 1994. Her roots started at Oregon Health and Science University, Portland, Oregon. From that work she has spawned two texts: Medicine Hands: Massage Therapy for People with Cancer *(Findhorn Press, 2007) and* Massage for the Hospital Patient and Medically Frail Client *(Lippincott Williams and Wilkins, 2005). Contact her at medhands@hotmail.com.*