# The Grapple of Massage

## Facilitating the optimal coordination of complementary and clinical care for complex patients of HIV/AIDS

**By Shona Thompson, RMT**

**Shona Thompson,** has been a Registered Massage Therapist since 2004. She had her own practice for 5 years, then started working at Casey House in 2009. She also has a small 'niche' home practice.

At the start of the HIV epidemic, the dialogue focused on words such as stigma, illness and death. Today our conversations are about treatment plans and wellness, long-term survivors and complex care. However, while people with HIV are living longer, many are living with significant medical and psychosocial complexities. These signs and symptoms are further complicated by the side effects of many of the medications used, and by secondary conditions that are the result of living with insufficient immune systems.[1]

In 1988, Casey House opened its doors as a specialty HIV/AIDS hospice, the first of its kind in Canada. From the beginning, it employed an RMT to work alongside doctors and nurses in the care of patients. This was especially unique during an era of extreme stigma, when the public felt an enormous sense of fear about the disease, and those diagnosed were being alienated by their family and friends. June Callwood, the founder of Casey House, felt that "touch" was an extremely important component to patients' care. For the first five to 10 years, Casey House offered treatment that was almost exclusively palliative in nature. Massage therapy was very active in the role of providing comfort to those who were were at the end of their lives.

Twenty-eight years later, as a sub-acute care hospital with 13 in-patient beds and community programs, Casey House is one of three hospitals in all of Canada that has a full-time staff member to provide massage therapy to patients, free of charge, as part of their treatment plan.[2] The role still includes palliative care, only on a much smaller scale. The new focus is on aging and HIV, as well as rehabilitation and management of the many side effects of medications.

At Casey House, we believe that complementary and alternative therapies are fundamental to supporting the health and well-being of the people under our care. We employ complementary therapies as an adjunct to medication regimens that help clients deal with pain, symptom management and depression. These therapies speak to our holistic approach to addressing the needs of the body, mind and spirit. Most importantly, they offer comfort to clients in all phases of their care, and contribute to enhancing their quality of life.

Patients can receive treatment in the massage therapy office or, in circumstances of limited mobility or palliative care, in the comfort of their own rooms. Once clients are discharged, they often continue to receive massage therapy as part of our community program. Massage therapy treatment plans vary depending on client goals, health, and therapist availability.

### Lack of presence and awareness

The presence of massage therapy in a hospital setting is very atypical. Unless other health care practitioners use massage themselves for personal wellness, or there is some other personal connection, it is unlikely that the average person would have extensive knowledge about the practice of massage. Therefore,

as we have proven time and time again, massage therapy as a profession must advocate for ourselves. Even in a facility where massage has been present for more than 28 years, and where we all sit together during hospital rounds each week and confer as peers in health care, it is essential not to underestimate the responsibility to be "present" at that table. The role is not only that of a caregiver, but also of an educator for both patients and health care professionals on the myriad of benefits of massage therapy treatments.

The therapeutic relationship with patients is supported by team collaboration and referrals. Our health care team meets on a weekly basis to discuss all aspects of treatment for each patient in the hospital. The community team meets weekly as well, and discusses the needs of patients based on priority of crisis management, problem solving and general updates, due to the large community population.

Each team member—whether it is a nurse or the chef who prepares a patient's meal each day—provides a unique perspective and information that is highly beneficial in thoughtful and successful care. Patients may talk about issues with various team members, and through professional and confidential knowledge transfer within the team, we are able to work more efficiently and constructively to help people in need.

### A panoptic therapy for a ubiquitous disease

People living with HIV self-report that complementary and alternative medicine is helpful in improving their quality of life, with relatively few risk factors associated with their use. People living with HIV also self-report that complementary and alternative medicine use helps to prevent and alleviate symptoms related to HIV, as well as side effects of treatment.[3]

Massage as integrative therapy after an HIV diagnosis is completely inclusive to all the issues our patients face today. It can address physical and emotional needs, and help patients, whether they are well supported, isolated or in palliative care., as well as survivors. It is my opinion that team collaboration helps to reach more people with various needs. It is through the mutual support in our roles—doctors, nurses, health care aides, social workers, massage therapists, recreation therapists, physiotherapists and nutritional supports—that we openly discuss the observations, opinions and needs of our patients so that we can make the best connections and referrals on their behalf.

Some clients may choose to only access the massage program. One client in particular, who has been rejected by friends and family since her diagnosis, comes for massage to help her cope with her severe sense of isolation and the fear of her HIV status being disclosed to her cultural community (which has a strong prejudice against HIV). She states, "I can share, I can have somebody to talk to. I can enjoy physical and emotional help at the same time."

At the end of 2015, there were 36.7 million people living in the world with HIV. Every day, two Torontonians are newly diagnosed with HIV. In fact, the rates of infection in Ontario are

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continuing at nearly the same levels as in the mid-1990s, and more than a quarter of these individuals are under the age of 30.[4] As we can see, the need for supportive care, like the disease, is on the incline.

**A call to action**

How do we see more Registered Massage Therapists working in inter-professional teams in hospitals, and other integrated environments? Admittedly, my position is unique. Government providers of health services provide no baseline funding for massage therapy. The massage therapy program at Casey House is supported by a grant from Casey House Foundation.

A great article by John Kania and Mark Kramer called "Collective Impact," talks about how "large-scale social change requires broad cross-sector coordination." In other words, collective impact initiatives are distinctly different from collaboration because collaboration involves a "centralized infrastructure and process that leads to a common agenda, shared measurement, continuous communication, and mutually reinforcing activities among all participants."[5]

Being a part of our professional association speaks to this. But what if we supported each other to make proposals for massage positions in various health care facilities across Ontario? What if those facilities found ways to financially support the need and desire for massage therapy? What if "Massage in Hospitals" could become as conventional as "Wash Your Hands"? (Ironically, although that mantra is instilled in our brains as part of health care, it was not formerly published as a set of guidelines until the 1980s.)

To live with HIV today means to live with a chronic and cyclical illness. There are long periods of wellness followed by unpredictable periods of illness. Typically, "clients struggle with five or more major medical problems complicating their HIV disease, including liver and heart disease, osteoporosis, brain infections and cancer. Roughly half experience HIV-related neurocognitive impairment, making it hard to hold down a job, to live independently, or to adhere to medication regimes."[4] As a massage therapist, I am addressing these conditions on a daily basis.

The need for increased capacity of services at Casey House brings with it the launch of a new Day Health Program in a purpose-built and state-of-the-art facility, to be opened in 2016-17. With this new facility, Casey House will provide a unique opportunity to implement changes that can positively influence the structure of all future health care networks. Casey House will take a holistic approach with an expanded inter-professional team, including massage, to bring together essential components of client health and well-being. Casey House will continue to model care in the Day Health Program to fit the needs of each client to create a tailored and innovative care plan.

Collaboration in health care is about accelerating the flow of knowledge in a team, for the best interests of mutual patients. In my opinion, we as a health care community are seeing many changes not only within our health care system, but also with the illness variables we see. We are evolving the ways we treat patients, and taking a more inclusive approach with the modalities that are available. We are having more conversations about using massage for pain, depression and harm reduction, which is needed if we want to keep up with the complexities of HIV. Massage therapy and its presence in inter-professional collaboration is a united approach that sends a positively reinforced message to patients that to "Live Well is to Stay Well." MT

**References**


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