

Should I Stay or Should I Go?

By Vocem Innominatum Patiens

I have congenital hereditary (primary) lymphedema of the lower body (core and legs). In 2001, my condition became significantly worse, most likely as the result of an overseas flight, without sufficient compression. Over the next eight years, I tried various types of treatment such as naturopathic and homeopathic remedies, non-prescribed compression, and Manual Lymphatic Drainage (MLD) sessions. Although I experienced varying degrees of success, none of these treatments were able to restrain the condition from its progressive, debilitating effect on my body. In fact, I suffered through many outbreaks of lymphorrhea and infections, a few of which required hospitalization.

The harsh reality was that the Canadian experience so far was not meeting my treatment needs... so I was off to Austria, with a sense of measured optimism.

It was within this context that I sought out help in 2009, from a centre of considerable expertise in Austria. Even though health-care providers in Ontario had been sympathetic and somewhat helpful in the attention to my condition, the degree of specialized treatment that I required was apparently only available...overseas.



Authors note

VIP (Vocem Innominatum Patiens—Latin for "voice of unnamed patient") is someone with lymphedema, who wishes to remain anonymous.

Lymphedema awareness and expertise still have a long way to go within the greater health-care community in Canada, while a few central European countries have longstanding awareness and familiarity with the condition and its complications.

Staying in Canada would mean the continuing deterioration of my condition and my quality of life. The Austrian opportunity held the promise of successful care at a world renowned facility for lymphedema – the Wittlinger Therapiezentrum, in Walchsee. The only potential drawbacks would be expense (no certainty of private or government insurance coverage), and uncertainty of success in treatment. With proper planning on the expense issue, only the certainty of success remained in my mind – that issue was resolved matter-of-factly by the harsh reality that the Canadian experience so far was not meeting my treatment needs...so I was off to Austria, with a sense of measured optimism and my spouse for support.

The following are some of the challenges I/we faced, followed by some of the benefits enjoyed. With this pro/con approach, the hope is that other patients in the same or similar position may make an informed choice of...should I stay or should I go?

Challenges

Austrian German is the business language of the Centre. English-speaking patients are in the minority, as the clientele is European, with most being native Austrians. The city of Walchsee has limited English-language services available; Proper-fitting garments are critical at the time of return air travel to Canada, so as not to undo any improvements achieved at the Centre; Researching Centre services before leaving Canada – whether for clothing needs, insurance receipt needs, VAT refund purposes, or other specific needs; The strict regime of scheduled activities (meals, treatments, exercise opportunities, etc.), which are in place by necessity (Austrian patients are covered by their insurance plans for specific regimes, which last three weeks.); and, Non-



lymphedema friendly facilities are on site – one must resist the temptations to use the sauna and whirlpools.

Benefits

The facilities are comfortable, convenient and the staff is accommodating. They made a point of assigning dining seating arrangements with other English speaking patients, making for a more pleasant social experience.

Communications and services are available in English both in the planning phase with the Centre, and in some reference material; The treatments are administered by fully qualified therapists, overseen by instructor physiotherapists, and in regular consultation with on-site medical staff. There are quantified weekly observation and measurements, plus a medical report at check-out providing details about improvement of patient's general (overall) health and volume reduction of edema etc; The duration of the stay

(my case – four weeks) is on an in-patient basis, with some flexibility in schedules, offering freedom to get out and about in the resort Tyrolean village of Walchsee or for day trips to nearby attractions.

Special dietary services and lymphedema-specific exercise classes are offered, including water-based techniques, as are hands-on workshops for self-care needs such as bandaging. The setting of the Centre is very helpful to the exercise regime...there is a pool (indoors) and there are outstanding and peaceful hiking areas nearby.


To fully address the sociological, psychological and physiological effects of lymphedema, great care and attention is evident for the whole of one's stay at the Centre: from the convenience of getting there (taxi from Munich, Salzburg or Innsbruck), to the regular medical monitoring and well-orchestrated schedule of treatments while there, to the full report, prescription and garment-fitting/provision upon check-out...all of which are offered

with the goal of optimal success of one's stay as the paramount factor.

Outcomes

The positive results I initially experienced as a result of my stay included a reduction in volume, increased mobility, restored self-image, elimination of pain and discomfort, and the ability to again wear proper fitting clothes. I was very pleased with my results.

For many patients, results are only sustainable for a few months, and many choose to venture to the clinic on an annual basis for the best results. However, as Hildegard Wittlinger once told me, "the ambiance of the Centre is tremendous for the path of being, doing and feeling better for those with lymphedema."

After a visit to Wittlingertherapiezentrum, you may feel like a renewed "VIP", too. 

Disclosure: This article was unsolicited and the author was not paid by the Centre or provided with any incentives for this review.

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