Mamma HELP – We assist women with breast cancer



WHY ARE WE HERE?

Breast cancer is the most frequent oncological diagnosis in women. In the Czech Republic, approx. 7,000 women are diagnosed with breast cancer every year and currently 80,000 breast cancer patients live here. The statistics say every $8^{th} - 12^{th}$ woman is affected with breast cancer during her life. Mamma HELP is a patients' non-profit organization to support women and their families while they fight the disease. Our dedication is to improve patients' quality of life (though a network of 8 Mamma HELP centers) and to inform the public about breast cancer incidence, prevention and treatment options (mainly through preventative lectures).

Inovation of the Project

Historically, a number of subjects have existed in the Czech republic to support women with breast cancer. Primarily, these organizations serve as a community for women who share their experience with the illness. We chose a different way of support at Mamma HELP. Our centers are open working days and offer free counselling and psychotherapeutic care provided by cured patients who are trained in client consultation and psychotherapy. Our inspiration came from the abroad where it works very well. Since 2000, we have opened 8 centers gradually all over the country. These are open Monday to Thursday (also Friday in Prague). Currently we employ 43 therapists there.

Even after twenty years, such a model serves good enough and needs no change. Our innovation is to build new centers in areas where no patients' communities or other services of this type exist, such as the Vysocina region, and where both patients and doctors call for this type of assistance.

Breast cancer affects many aspects of patient's life – health, psychical, social and economic. In the frame of physical changes, for instance, patients appreciate practical information about solving possible side effects of treatment, adjusting diet during and after treatment, use and offer prosthetic aids (breast replacement with a prosthesis – breast form), etc. Neither doctors, nor nurses in oncology offices have the capacity to provide this information. Of course, information may be found on the internet, however the source reliability remains uncertain. And our centers are the right place where our clients may obtain this valuable information. The project scope is to cover these weak places or gaps in the health system.

At the same time, the individual consultation service we provide fulfills the long-term program goal of ECPC (European Cancer Patient Coalition), whose active member we are. The care for patients should not only include surgery, chemotherapy and radiotherapy, but also care for their psyche and assistance with solving related problems, especially social, all these preferably in the form of individual approach.

New Approach to the Target Group and Its Involvement

From the legal view, Mamma HELP patient organization is an association, whose founding members were female patients and their oncologist. Many of them still act in the association as volunteers, some became part time employees and their enthusiasm and sense for reliability is a result of this.

However, from the beginning, the target audience of the project are not only the members of the association, but all women with breast cancer who contact us. The key is that the therapists who take care of clients have experienced breast cancer themselves, so they understand the target audience very well.

In order to be capable of providing qualified assistance to the client overcoming a psychological load of a serious oncological disease, the therapist must go through several psychological testings and a number of training seminars (and participate in regular supervisions focused on psycho hygiene). These are not intended to replace psychological education, but to gain basic techniques needed to lead an interview with a woman, so that the therapist can make use of her own experience with the disease. Psychologists who work with us on a long-term basis, confirm effectiveness of such an approach – they are not able to provide the experience themselves.

A bonus of this approach is also the fact, that many therapists were clients of the center at first. Thus their knowledge of the provided support is from both sides – as a client and as an assistant providing support. Their decision to work for us and assist women who find themselves in the same situation is a proof that such assistance makes sense.

Innovation in the Way of Implementation and Effectiveness

The centers visits frequency shows the need for our way of assistance. There are over 6,000 visits per year, a number of women contact our therapists repeatedly and they guide them through the whole demanding treatment process. We are also here for women with some problems after the treatment and also for those struggling with a relapse of the disease. The family members or friends accompany the patients more often and we are able to help them as well.

Since the beginning, individual counselling for clients is free of charge, the woman can take any time needed for the consultation with a therapist and everything is being done in an intimate and safe environment. All these is appreciated by our clients very much. A "one-on-one" talk brings them not only relief and cleansing, but it is also efficient. Above that, our ethical code and way of processing the documentation from such a visit, which we started to implement two years ago, guarantees the client privacy and safety.

To make our service the most efficient as possible, we cooperate with several specialists. Each center has its own specialized guarantor (oncologists, surgeons, geneticist) and we closely collaborate with medical centers (e.g. Masaryk Memorial Cancer Institute in Brno or The Mammary Diagnostics Association). Our educational materials are available at some selected medical facilities. Some doctors delegate the patients to our centers themselves.

Reaction to Changing Needs and Conditions

We react to the changing needs of our clients, therefore apart from physical individual assistance we also launched e-mail and phone consultations a few years ago. Again, these are provided by our therapists, recovered patients. There are also set hours when specialists – a psychologist or oncologist - are available over the phone. We also operate online medical consultation and social consultation where a social worker responds to e-mail inquiries regarding social issues. Thus it is up to our clients to make their choice what kind of assistance is the most suitable for them (some live far away from our centers, so they can at least use our toll free support).

During the past few years, an increasing number of young women, mothers, have been been diagnosed with breast cancer. It was upon their impulse that we launched project 'How do I tell my children about my disease' in 2016. This focuses on breast cancer patients, mothers, who have encountered a problem how to communicate their disease to their children. The project is currently implemented in a pilot phase at the Prague MH center and will be spread to our cities in the future.

Over the last two years, a strong base of sympathizers and active patients has been created in Usti nad Labem. Therefore, our plan is to open a new, 9th center here in the near future to respond to the need of the local community.

Innovation in the Perception of the Project by the Public

Each of the 8 centers has its background and is integrated into its regional environment. On the other hand, Mamma HELP is perceived by the public as a complex, as its services everywhere are provided in the same way and the same quality.

We actively cooperate with other organisations and we complement each other's services. Such an example is the Good angel foundation, which provides oncological patients with financial support (including women with breast cancer) during their treatment. On the contrary, we provide their clients psychological support.

We enhance the public perception of our individual consultations and overall information about breast cancer though our campaign October in pink (October is internationally known as a breast cancer awareness month). Apart from many education events for public (preventive presentations) a road show exhibition of artistic photos entitled Woman and breast cancer is currently running.

Our latest medial partner supporting our key activity (individual counselling) is the international company <u>Young and Rubicam</u>, which prepared a new spot for us. It will be launched on public Czech Television this spring and will also screen in a number of cinemas across the country.

THE OPERATION AND FINANCING OF THE ORGANIZATION

We are a non-profit patient organization with the legal form of association. We register over 700 members. Our headquarters is in Prague and the management consists of 9 people. 43 therapists work in the centers today (based in Prague, Brno, Plzen, Ceske Budejovice, Hradec Kralove, Olomouc, Zlin and Prerov).

A coordinator is in charge of each center, and is responsible for its operation and obtaining the majority of finances needed for its operation. As all our individual care is provided free of charge, we rely on help from our donors and partners. Currently the most significant part of our financial sources comes from individual donors (mainly through direct mailing). Apart from these, our finances arise from subsidies and grants from public sources, public collections, membership fees and the sale of our art therapy products. The list of all of our partners and sponsors is here. We would not be able to offer our clients anything they expect and for what they contact us for without such funds.

CLIENT TESTIMONIES about Individual Counselling

- Therapists gave me information about what to do in the situation I found myself in. They gave me
 hope again that I will overcome the disease and would get back to my normal life after the
 surgery. Ivana K.
- I once headed to the Mamma HELP center from my oncology check-up. It was here that I found everything I was missing understanding and experienced friends, and a new hope that I strongly held to. Nine years have already passed since then, I am happily married and we have two children. I drop by at the center everytime I pass around. I owe them for not giving up at that time. Jana S.
- To trust and talk to someone who went through the same experience is a balm to my soul. Someone, who understands me. Mrs. Pokorna