

Highlights from EUROPA DONNA's 2nd Metastatic Breast Cancer Advocacy Conference



7 – 8 June 2019 Milan, Italy

EUROPA DONNA – The European Breast Cancer Coalition's 2nd Metastatic Breast Cancer Advocacy Conference provided information on current advocacy priorities and gave participants the opportunity to share strategies to advocate with and for other women with metastatic breast cancer (MBC). At the introductory session, 35 MBC advocates from 27 of the Coalition's 47 member countries gave a brief history of their personal fight against MBC and as advocates. Many of them have been living with MBC for 3 or 4 years, while some have had it for much longer and a few were newly diagnosed. Most were middle-age or younger, and some were diagnosed at a young age, for example a participant had been diagnosed with early breast cancer at 31 years of age and with MBC at 33. Several were diagnosed de novo. They had metastasis to the bone, liver, lung and brain. They were running blogs and spreading knowledge through Twitter and Instagram accounts and Facebook groups, organizing MBC conferences, producing videos, participating in radio shows and submitting articles to local newspapers to heighten awareness, and helping other women navigate the journey of MBC. All were advocates gaining strength and knowledge from each other and the conference: sessions on current therapies, psycho-social support, the benefits of physical activity for women with MBC, nutrition, insurance/financial issues, return to work/legal issues, support groups, and psychological counseling services. EUROPA DONNA has made MBA an advocacy priority and is involved in multiple initiatives in Europe, internationally and at a local level to address the unique needs of this group of women. By training women with MBC, we prepare more women who know the issues first-hand to advocate on behalf of others with the disease. This report highlights some of the main messages from the conference.



2nd Metastatic Breast Cancer Advocacy Conference participants.

Current therapies/research for MBC

Olivia Pagani, Breast Cancer specialist at the Breast Unit of Southern Switzerland and member of the ED Executive Board, gave an overview of the latest in MBC treatments and research. She stated that the main principles of modern breast cancer treatment (both in the early and advanced disease setting) include a multidisciplinary approach using evidence-based medicine and individualized (tailored) therapy, together with psychosocial and supportive care and symptom-related interventions. The treatment depends on many factors such as patient age and menopausal status, tumor characteristics, metastatic spread and sites, previous treatments, and available treatments in the patient's country. MBC is currently an incurable but treatable disease; goals should be the control and regression of disease, prolong life and improve symptoms and quality of life. Patient preferences must always be taken into account and patients should be encouraged to actively participate in their care. Patients, families and caregivers should be invited to participate in decision-making.



ABC Consensus Guidelines

EUROPA DONNA recommends that advocates become knowledgeable about evidence-based guidelines and learn about current best practices. In this way we can advocate for appropriate services and methods of support for MBC patients. The International Consensus Conference for Advanced Breast Cancer is a major international breast cancer conference held biennially in Lisbon, Portugal. Its primary aim is the development of international consensus guidelines for the management of ABC patients. Representatives of breast cancer patient advocacy groups are invited to participate in the conference and to actively contribute to the scientific program and the consensus session. Dr. Pagani discussed the following guidelines resulting from the ABC conferences:

A biopsy (preferably providing histology) of a metastatic lesion should be performed, if easily accessible, to confirm diagnosis particularly when metastasis is diagnosed for the first time. Biological markers (especially HR and HER-2) should be reassessed at least once in the metastatic setting, if clinically feasible.

A small but very important subset of patients with ABC, for example those with **oligo-metastatic disease or low volume metastatic disease** highly sensitive to systemic therapy (e.g. HR+ and HER-2+), can achieve complete remission and a long survival. A multimodal approach, including local-regional treatments with curative intent, should be considered for these selected patients.

Endocrine therapy is the preferred choice for HR+ advanced breast cancer: it is as effective and it has fewer side effects than chemotherapy. Exceptions: concern or proof of endocrine resistance; need for fast response due to disease extent and/or symptoms.

Regarding **young women** and MBC, the BCY4 (Breast Cancer in Young Women International Conference) panel endorses the ABC4 ESMO-ESO statement: Many trials in HR+ ABC have not included pre-menopausal women. Despite this, we recommend that young women with HR+ ABC should have adequate ovarian suppression or ablation (OFS/OFA) and then be treated in the same way as post-menopausal women with endocrine agents with or without targeted therapies (e.g. CDK4-6 inhibitors).

Future trials exploring new endocrine-based strategies should be designed to allow for enrollment of both pre- and post-menopausal women, and men.

Sequential single agent **chemotherapy** should be generally preferred to combination chemotherapy as it produces less toxicity. There is currently no data to support optimal sequence. Combination chemotherapy is reserved for patients with: rapid clinical progression, life-threatening visceral metastases, or a need for rapid symptom/disease control. The chosen regimen should be evidence-based, with proven efficacy and acceptable toxicity.

For non-BRCA-associated **triple negative ABC**, there are no data supporting different or specific chemotherapy recommendations. Therefore, all chemotherapy recommendations for HER-2 negative disease also apply for triple negative MBC.

In triple-negative MBC patients (regardless of BRCA status), previously treated with anthracyclines with or without taxanes in the (neo)adjuvant setting, carboplatin demonstrated comparable efficacy and a more favorable toxicity profile, compared to docetaxel, and is therefore an important treatment option.

Anti-PDL1 immunotherapy (Atezolizumab) in combination with a taxane (Nab-paclitaxel) has shown to be effective as 1st line therapy in patients with PDL1+ triple negative disease. Further evidence is needed but these data, the 1st showing efficacy of this class of agents in breast cancer, are promising and open the door to an additional possibility in this disease subtype.

In BRCA mutated patients, Parp-inhibitors (Olaparib and Talazoparib) proved to be effective and well tolerated and are becoming an important component of the treatment strategy. Olaparib has also shown a survival benefit vs standard treatment.

Anti-HER2 therapy should be offered early to all HER2+ advanced breast cancer patients unless contraindicated (or unavailable). Disease control and survival have greatly improved over the last years. Optimal duration of anti-HER2 therapy for metastatic breast cancer (when to stop) is unknown. Several drugs are now available in addition to trastuzumab (e.g. Pertuzumab and TDM-1).

HER2Positive MBC: 2nd line and beyond: after 1st line trastuzumab-based therapy, T-DM1 provides superior efficacy relative to other HER-2-based therapies in the 2nd line (vs. lapatinib + capecitabine) and beyond (vs. treatment of physician's choice).

 The guidelines developed following ABC 1 – 4 conferences can be found here: <http://www.abc-lisbon.org/>

Dr. Pagani went on to discuss **biosimilars**, which are designed to be “copies” of biologic drugs (i.e. a drug derived from living cells). They aim to be essentially the same as their reference biologic or originator but have a degree of natural variability. For a biosimilar to receive regulatory approval it has to prove that it is equivalent to the originator. This means that the clinical trial process is shorter for the biosimilar than for the originator, which should make the biosimilars available more quickly and help to provide drugs that are significantly less expensive than the originator.

An important research project is **AURORA**, an international program to use molecular screening in women with MBC, in which ED is involved. Primary and MBC tissue as well as blood specimens are being collected and characterized on a large scale. If a genetic mutation is found, a clinical trial that tests a new treatment designed to target that mutation may be proposed to the patient (if the physician finds it appropriate). If no drug or clinical trial is available for a mutation, or if no mutation is found, the physician will choose the best available standard treatment for the patient. A total of 1,000 women and men from about 80 hospitals in 14 European countries are expected to take part in this project.

Objectives of the study are to: improve the understanding of MBC and its underlying causes; determine why some tumors respond poorly to standard treatment while others respond well; and identify potential predictive biomarkers for response and resistance to commonly applied anticancer agents. AURORA will be the first broadly international program of its

kind to focus on Metastatic Breast Cancer in order to improve our understanding of the disease with the hope to develop individualized cures for the future. Europa Donna represents the interests of patients on the Steering Committee of the AURORA Study.

The ABC Global Alliance is a multi-stakeholder platform for all those interested in collaborating in common projects relating to advanced breast cancer (ABC) around the world. Launched during the World Cancer Congress in Paris on 3 November 2016, the aim is to continue the work developed through the ABC International Consensus Conference and Guidelines. Its mission is: to improve and extend the lives of women and men living with ABC in all countries worldwide, to fight for a cure, to raise awareness of advanced breast cancer and lobby worldwide for the improvement of the lives of ABC patients. EUROPA DONNA – The European Breast Cancer Coalition is a member of the ABC Global Alliance.

Psycho-Social Support: what patients need

Luzia Travado, Head of Psycho-Oncology at the Champalimaud Clinical Center in Portugal, gave a presentation on psycho-social support.

She discussed the consequences of psychological morbidity in cancer patients in general: the impact on clinical outcomes can include a deterioration of quality of life, reduced compliance with treatment, less efficacy of chemotherapy, higher perception of pain and other symptoms, a shorter survival expectancy, longer hospital stay and increased costs, a higher burden for the family and a higher risk of suicide. For those living with MBC, an incurable, chronic disease associated with a shorter survival time, many challenges persist: frequent medical procedures, chronic side effects (e.g., occupational disability, pain, fatigue, cognitive impairment, sexual dysfunction) and practical concerns (e.g., work and family role disruption, financial strain). People with MBC are at risk for emotional distress, including symptoms of depression and anxiety as well as existential distress and loneliness. Distress has been shown to peak around the time of diagnosis and then it declines during the year; almost 1/3 of women studied met criteria for depressive disorder and 6% met criteria for an anxiety disorder. Main themes in MBC patients are quality-of-life concerns, including physical symptom burden, emotional distress, body image disturbance, and disrupted daily activities; social constraints, like the disclosure of cancer-related concerns which may exacerbate patients' distress; and many people experience a heightened awareness of life's brevity and search for meaning in their cancer experience. Those at increased risk for distress and worse psychological adjustment are: those of younger age and with more disease progression; people with stronger physical symptoms, such as pain, fatigue, insomnia, and gastro-intestinal issues; those with functional impairments, like lymphedema; those who are single, divorced, separated, widowed, living alone; people with children younger than 21 years of age; those with a poor marital relationship; people experiencing economic adversity; those with past psychiatric history, especially depression; and patients experiencing cumulative stressful events.

According to the International Psycho-Oncology Society's Statement on Standards and Clinical Practice Guidelines in Cancer Care (2009 updated 2014): psychosocial cancer care should be recognized as a universal human right; quality cancer care must integrate the psychosocial domain into routine care; and distress should be measured as the sixth vital sign after temperature, blood pressure, pulse, respiratory rate and pain. Types of psychological interventions for MBC include: psycho-educational interventions (information about the disease process, coping with disease and resources available); individual psychotherapy (targets emotions, coping, self-efficacy and self-esteem); cognitive-behavioral therapy (CBT) (targets maladaptive thoughts, feelings and behaviors that contribute to symptoms); and group interventions (by patients or professionals; targets social support, de-stigmatization, communication, hope and meaning in life). In supportive-expressive group psychotherapy (SEGT) for MBC patients main themes include building bonds, expressing emotions, detoxifying the idea of death and dying, redefining life priorities, increasing the support of friends and family, improving the doctor-patient relationship and improving coping skills. In the treatment of existential suffering, focus is on controlling physical symptoms; providing a supportive presence; encouraging life-review to assist in recognizing purpose, value and meaning; exploring guilt, remorse, forgiveness, and reconciliation; facilitating religious or spiritual expression; reframing goals; and encouraging meditative practices (focusing on healing rather than a cure). Goals of Meaning Centered Group Therapy for cancer patients include: promotion of a supportive environment; a greater understanding of possible sources of meaning before and during cancer illness; discovery and /or maintenance of a sense of meaning in life during a cancer illness; improved quality of life; and optimization of coping with illness through an enhanced sense of meaning and purpose.

CALM Therapy (Managing Cancer and Living Meaningfully) for advanced cancer patients focuses on symptom management and communication with health care providers; developing spirituality, sense of meaning and purpose; making changes in personal relationships; and planning for the future, having hope and considering mortality to reduce and prevent psychological distress. This therapy showed a 52% reduction in depressive symptoms after three months and a 65% reduction in six months of follow-up, versus 35% in the control group of a randomized clinical trial.

In the DistressBrain project (2015-2020), the effects of stress-associated factors on the tumour microenvironment are measured in patients with MBC. In this study, it was found that 37.7% of MBC patients studied have significant levels of psychological distress and disorder; 42.63% of MBC patients have significant anxiety symptoms; and 32,79% of MBC patients have significant symptoms of depression. Psychological distress has been shown to have an impact on autonomic, neuroendocrine and immune systems of our body, affecting cancer progression and negative health outcomes. Psychosocial interventions helping cancer patients learn stress management may not only reduce depression and anxiety and modulate biobehavioral processes but are associated with greater survival and a longer time until recurrence.

An international, multi-disciplinary team of patients and health care professionals (HGP) from 26 countries worldwide met at the 2nd MBC Summit in Vienna in October 2017 to discuss comprehensive recommendations to improve communication, based on a review of international medical (e.g., ASCO, ESO-ESMO) and nursing guidelines on the current standard of care, aiming to provide de facto advice on how to best achieve it. The PALiMo recommendations (Prepare the consultation in advance--Ask the patient if they have understood explanations and whether they agree

regarding next steps--Listen to find out if the patient has any concerns or questions--Motivate and encourage patients for the long patient journey together) were the outcome and define a set of suggestions describing specific processes to assist HCPs in conversations with their patients, from the initial diagnosis to finding the appropriate treatment or talking about end-of-life care. Three overarching topics stood out as being important for good communication: information and understanding; effective, open communication; respect patient values, needs and preferences. These topics form the basic structure and guided the development of the recommendations.

Benefits of Physical Activity for Women with MBC

Professor Dr. Karen Steindorf, Head of the Division of Physical Activity, Prevention and Cancer at the German Cancer Research Center (DKFZ) and the National Center for Tumor Diseases (NCT) in Heidelberg, Germany described the benefits of physical activity for women who have MBC.

Dr. Steindorf started off by explaining that in the past, cancer patients were advised by their doctors not to engage in sports, especially during the acute treatment phase. As more studies have been conducted over time the broadness of effects of exercise as a supportive therapy has become increasingly accepted, but still today not all patients and health professionals are informed or have access to adequate facilities. She theorized that in the future exercise will become a standard therapy in supportive cancer care based on the major impact on quality. First results on anti-tumoral effects of exercise may speed up this development, if confirmed by clinical trials.

Exercise and physical training can potentially positively influence the following effects in cancer patients: physiological (e.g., aerobic fitness, balance and functional capacity, post-surgical complications, chemo-induced cardiotoxicity), biological (e.g., inflammation, immune function, hormone regulation, cortisol, plus risk of co-morbid diseases like diabetes and osteoporosis), psychosocial (group support, attention of trainer, structuring the day, self-efficacy) and psychological (quality of life, fatigue, mental well-being, pain, sleep quality, cognitive decline, depression, anxiety and psychological distress).

Today's exercise recommendations for cancer patients in general are: avoid inactivity; start exercising as early as possible; to the extent possible, adhere to the general Guidelines of Physical Activity of at least 150 minutes per week of moderate-intensity aerobic activity plus two to three sessions per week of moderate-intensity resistance exercise; exercise routines should be individually tailored and progressed; clinicians should advise cancer patients correspondingly; exercise is safe for people with cancer when appropriately prescribed and monitored. Contraindications to exercise include: incomplete wound healing; less than 24 hours after chemotherapy; low thrombocytes; acute bleeding; anemia; severe pain, nausea and/or dizziness; fever and/or acute infections; severe or acute neurologic disturbances. Specific topics need individual considerations for cancer patients including immune suppression, bone metastases, port, stoma, weight loss, lymphedema, polyneuropathy, osteoporosis and heart insufficiencies. Before starting an exercise regimen, cancer patients should undergo a medical examination and interdisciplinary exercise planning and should be supervised while training.

Very few studies about the effects of exercise on patients with MBC have been conducted and they have been small. A total of 26 research studies from 12 different countries have been conducted on the effect of exercise interventions for individuals with advanced cancers. Overall, 2,053 subjects were studied, of which 71% completed the interventions. Results yielded improvement in aerobic capacity in 14 of the 19 studies, strength in 11 of the 12 studies, physical function in 9 out of 9 studies, fatigue in 11 of 19 studies, and quality of life in 10 out of 19 studies. Although these results seem promising the review is based on few studies, and it includes uncontrolled trials and with heterogeneous interventions and small sample sizes.

The PREFERABLE (Project on Exercise for Fatigue Eradication in Advanced Breast cancer to improve quality of life) study will help fill in some of the knowledge gap. The consortium includes institutions from 6 European countries and EUROPA DONNA – The European Breast Cancer Coalition is a partner in this initiative. PREFERABLE focuses on the role and benefits that structured and individualized exercise can have in the treatment of patients with breast cancer that has metastasised. Running for five years starting in January 2019, this project investigates if exercise can improve quality of life of this patient group. The aim is to improve the standard of care in MBC patients by improving the quality, effectiveness and cost-effectiveness of supportive standard care in a palliative setting. The leaders of the study hope to generate solid and conclusive evidence of the beneficial effect of exercise on cancer-related side-effects and patients' quality of life and to contribute towards reshaping medical practice, and improving clinical guidelines and recommendations.

Nutrition and MBC

Anna Villarini, Nutritionist Biologist and Epidemiologist at the Istituto Nazionale dei Tumori in Milan, Italy, spoke on Nutrition and MBC. She stated that a healthy diet and good nutrition are essential for women with MBC.

Factors associated with cell growth, carcinogenesis and cancer promotion are hormones and growth factors (insulin, insulin like growth factor I (IGF-I) and vascular endothelial growth factor (VEGF)) and inflammatory factors (cytokines). In order to preserve low insulin levels, it is recommended to reduce the intake of high glycemic and insulinemic index foods, such as milk, sugar, refined cereals, white bread, desserts and fermented milk products, potatoes and sweetened drinks.

High circulating levels of insulin also upregulate the hepatic synthesis IGF-I; high IGF-I levels are associated with worse prognosis for several types of human cancers, including breast cancer. VEGF production is induced by insulin and IGF-I, and it is high in obese people and decreases with weight loss. A growing body of evidence in humans suggests strong associations between VEGF levels and aggressive cancers. Obesity and abdominal obesity have also been associated with subclinical inflammation. Dietary patterns that promote inflammation include: Western dietary patterns, processed and red meat, salt, hydrogenated fat, refined flours, potatoes, refined cereals, fast food and alcoholic beverages. Dietary patterns associated with anti-inflammatory foods are: Mediterranean and Macrobiotic diets, fruits, vegetables, unrefined cereals,

pulses, bluefish, whole rice, barley, extra-virgin olive oil, onions, apples, raisins, cruciferous vegetables, green tea, turmeric, ginger and dark chocolate.

In addition, physical activity such as 30 minutes of walking every day is recommended to reduce abdominal adiposity, inflammation, insulin and glycaemia (hyperglycaemia is one factor most associated with the worst prognosis in metastatic breast cancer).

Regarding supplements and antioxidants in MBC, generally pro-oxidants reduce tumour growth and anti-oxidants promote tumour growth. People with MBC should take supplements only when they have been advised by their oncologist who is able to assess potential risks and benefits.

During therapy for MBC collateral effects including fatigue, bitter/metallic taste in mouth, mucositis, nausea, weight gain/loss and diarrhea can be reduced through lifestyle adjustments. To combat fatigue: engage in moderate physical activity; eat foods containing magnesium and vitamin B1 (wholegrains, nuts, soy and derivatives, dried fruit); avoid consuming central nervous system stimulants (coffee, cola, tea, chocolate) in the afternoon or at night; do not stay in front of the TV or computer for long periods before going to bed; maintain a regular sleep/wake rhythm; stay in bed long enough to regain energy but never more than necessary; do not smoke. For a bitter or metallic taste: do not force yourself to eat foods that taste bad; eat small amounts throughout the day instead of eating big meals; use salad dressings or vinaigrette and flavor foods with herbs, spices and lemon; avoid red meat, chocolate and coffee; avoid eating with metal cutlery and wearing metal objects except gold or silver. For prevention of mucositis: limit baked foods rich in fiber and excess protein foods (especially animal products) and instead eat brown rice, pulses and vegetable cream. For a light case of mucositis, repeatedly rinse with half a glass of water and a tablespoon of acidulated umeboshi. In case of severe mucositis or difficulty in eating tell your medical doctor. For nausea, avoid: foods that are very sweet, fatty, greasy, spicy, fried; any odor that can cause a sensation of discomfort; eating fish; drinking large quantities of liquids with meals. Eat little and often so that the stomach is never completely empty. Drink small sips of a ginger herbal tea or a small glass of water with a tablespoon of sodium bicarbonate. For diarrhea, avoid: milk; foods that are too hot or too cold; carbonated, alcoholic and caffeinated drinks; fruit and fruit juices; sugar and refined cereals; cheese and eggs; smoking. Instead, eat: small but frequent meals; brown rice cream, pasta or other grain cereal; carrot or pumpkin soup; plain yogurt; fish (if you don't have nausea) or white meat. Drink at least a liter of water or herbal tea a day. If your weight changes during treatment, it is important to consult your medical doctor and ask to be referred to a nutritionist who will help you to manage your diet according to your tastes and habits.

Activity Trackers and Physical Activity Apps for MBC

Dr. Anne May of the Julius Center, University Medical Center Utrecht, The Netherlands, gave a presentation on activity trackers and physical activity apps for MBC. Launching off from the conclusions drawn by Karen Steindorf in her presentation that exercise therapies for patients with cancer are generally safe, feasible and probably indicated in all phases and that there are manifold positive effects on side-effects and prognosis, Dr. May stated that people should in most cases keep steady or increase their physical activity levels during treatment e.g., by using an activity tracker in combination with a supervised programme. The use of an activity tracker has several advantages: direct tracking of daily physical activity; automated feedback on daily activity levels as well as time seated; feedback can be integrated with other app-based behavioral change tools.

Commonly known examples of tracker brands are MiBand, Fitbit, Garmin; Polar and Apple and prices can range from 30 Euros for the more simple models to 100 to 500 Euros for models with numerous features. At a minimum, steps per day and active minutes per day are tracked; in more complex models, sleep, heart rate, specific activities, diet, body weight, and well-being can also be tracked or self-registered.

Evidence shows that in general physical activity interventions including wearables and smartphone applications increase physical activity. Fitbit usage without further guidance in patients with breast cancer during chemotherapy was shown in a study to have low adherence (below 50%) and the recommendation is therefore to combine the activity tracker with a supervised intervention. In the ACTIVATE randomized trial, for example, the Garmin Vivofit 2 activity tracker was given to patients with breast cancer after treatment was completed with one behavioral feedback session and a goal-setting session plus five telephone-delivered health coaching sessions over the course of 12 weeks. The study results showed positive effects on physical activity and sitting time. In a similar trial called the UMBRELLA Fit study, patients were motivated by the tracker to be physically active and it created more awareness of a sedentary lifestyle.

Goal setting was found to be the most motivating factor when a realistic goal is set. Ten-thousand steps per day is often the standard, but this advice is not based on evidence. Recent research in older women shows advantages from 4,400 to 7,500 steps per day. A tracker with heart rate monitoring is preferred.

The PREFERABLE trial (<https://www.h2020preferable.eu/>) in which Europa Donna is involved will be the first large-scale exercise study of women and men with MBC to make use of an activity tracker combined with an interactive app and supervised exercise programme to test whether exercise can improve fatigue and increase quality of life in these patients.

Exchanging Advocacy Tools and Experiences

A panel session on advocacy for several topics of importance to people with MBC was held to close out the afternoon and led by Europa Donna board members. As Europa Donna surveys and other research have shown that women with MBC often face unresolved professional, legal and financial issues, such as workplace discrimination, loss of job and thus income, and increased medical expenses; as women with MBC do not receive sufficient psycho-social support; and as women with MBC need more support for family matters, it was decided to address these issues.

First panel member Elizabeth Bergsten Nordström of Sweden tackled the subject of insurance and financial issues; Ellen Verschuur of the Netherlands addressed return to work and legal issues; Mona Elzayat of Austria spoke about using support groups, and Paola Mosconi of Italy presented on psychological counselling services for patients and partners. After that, all assembled took part in the World Cafè, breaking out into four groups to discuss in-depth each of these topics, sharing advocacy strategies and brainstorming next steps to best address the issues. They rotated into the different topics until everyone had discussed all of the matters. Finally, everyone came back together with the four panelists summarizing discussion from table results.

Findings from the Europa Donna questionnaire: MBC and psycho-oncology, physical activity and complementary therapies

In a Europa Donna survey on the topics of MBC and psycho-oncology, physical activity and complementary therapies, we received 23 responses from women with MBC.

A total of 60% said that free psycho-oncology services are available to MBC patients in their institute or hospital and an additional 17% said they were available but very limited. 77% stated that these services are available outside their institute or hospital about evenly split among patient groups, other cancer support groups, in other centres or privately only. Where services are available, 24% said they only receive them if the medical oncologist says they are necessary, 41% said a patient needs to request services (self-referred), and 35% claimed that all new MBC patients are offered psycho-oncological support. Of those who took part in these services, 53% said they were very helpful, 18% somewhat helpful, 24% a little helpful and the remainder unhelpful. Psycho-oncology services are free and available to family members of 43% of respondents and for 23% they are available but very limited. For 74% surveyed, psycho-oncology services are available to family members outside of their institute or hospital, through their patient groups, other centres or privately. Of the 7 respondents whose family members had taken part in services available, one said it was very helpful, 4 somewhat helpful, one a little helpful and 1 not helpful.

With regard to MBC and physical activity, 38% said that they are engaging in more physical activity since they were diagnosed with MBC, 35% said they were doing the same amount and 27% said they are doing less. Of those exercising less, 69% said it was due to disease spread limiting their ability to exercise, 23% said they exercise less now because they fear hurting themselves, and 8% said they fear that exercise might be bad for them. Of those doing more exercise since diagnosis, 90% said it was very helpful to their quality of life and 10% said it was a little helpful. A total of 48% said there is a physical activity programme for MBC patients in their institute or hospital and of those 64% can use the service for free. And 73% have specialist physical activity advice available to them outside of their institute or hospital, either via a patient group, cancer league, rehabilitation centre, private gym or through private consultations. Half have to pay for the service and half said it is provided free of charge. 84% said their medical oncologists discuss the benefits/harms of exercise and that it is generally good to do so. About 10% use specific MBC apps to help them exercise, and they both claim it is somewhat or a little helpful to their quality of life.

A total of 74% use other complementary or integrative therapies, including aromatherapy, hypnosis, meditation/prayer, yoga, Tai-chi, Reiki, acupuncture, massage, medical marijuana, CBD (Cannabidiol), herbal/natural supplements and reflexology, and they all said it was very, somewhat or a little helpful. Of these, 84% always tell their medical oncologist team that they are also doing complementary or integrative therapies, 11% tell them if they are using natural or herbal supplements but not meditation and other physical therapies.



Piazza Amendola, 3
20149 Milan, Italy
Tel: +39 02 3659 2280
Fax: +39 02 3659 2284
Email: info@europadonna.org
www.europadonna.org
<https://mbc.europadonna.org>

EUROPA DONNA gratefully acknowledges



for their support