

Metastatic Breast Cancer Summit:

Helping meet patient needs

**The role of patient groups in influencing policy:
The Metastatic Breast Cancer 5 Point Plan**

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28 years of support and advocacy Experiences from Sweden

BRO – The Swedish Breast Cancer
Association

Swedish Forum of EUROPA DONNA
11 000 members



The Help line of The Swedish Cancer Society Telephone and e-mail

- **Information, answer to questions, support**
- **9 000 contacts per year**
More women than men both by telephone and mail
- **Patients, relatives and persons with symptoms**
- **Most of the questions about breast- and prostate cancer**
- **Nurses trained in oncology and communication**

The needs

of patients?

- 19% Newly diagnosed
- 42% Under treatment
- 16% Advanced disease
- 23% After treatment or cured

of relatives?

- 20% Newly diagnosed
- 30 % Under treatment
- 33 % Advanced disease
- 7 % After treatment/cured
- 10 % Deceased

The “5 Point Plan”?

Details



What is the 5 point plan? It is a series of standards that should be in place to improve the wellbeing of people with Metastatic Breast Cancer breast cancer.



What are the objectives? Greater awareness around the characteristics and burden of the disease as well as the elements that needs to be changed in Order for people affected to be able to live longer and with good quality of life.



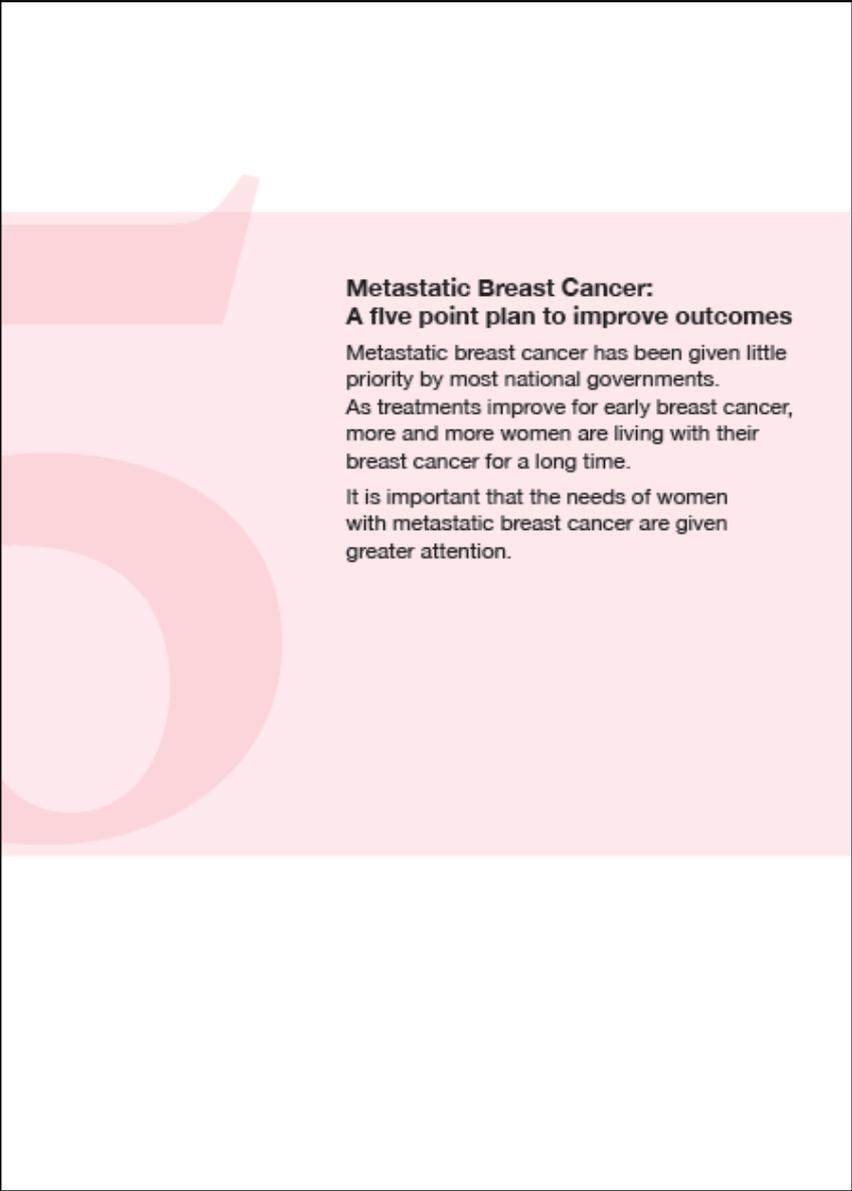
Who develops it? The Swedish Breast Cancer Association (BRO)



What is the status? The Plan has been developed for discussion and comments during the Summit. The target is to be endorsed by as many groups as possible in order to maximize its strength



Who is it aimed at? It is developed by a patient group, for patient groups, to facilitate policy discussions around mBC



**Metastatic Breast Cancer:
A five point plan to improve outcomes**

Metastatic breast cancer has been given little priority by most national governments.

As treatments improve for early breast cancer, more and more women are living with their breast cancer for a long time.

It is important that the needs of women with metastatic breast cancer are given greater attention.

The “5 Point Plan”

The elements



Each country should have a comprehensive national cancer registry with funding secure for the long term.

- Data should be published, at least annually, including:
 - Number of newly diagnosed metastatic breast cancer patients and number of patients living with a prior diagnosis
 - Treatments received by individual patients
 - Cause of death
- The tumour characteristics should be tested and recorded when metastatic disease is diagnosed, regardless of any earlier pathology

The “5 Point Plan”

The elements



Guidelines should be in place for the treatment and care of patients.

- National guidelines for the management of metastatic breast cancer patients should reflect current international standards
- Patients with a prior diagnosis of breast cancer should have early access to the breast cancer team if they have symptoms suggestive of a relapse
- Protocols for the delivery of treatment and care should be in place and their application audited

The “5 Point Plan”

The elements



All patients should receive optimal care for their personal circumstances.

- All physicians should be aware of the signs and symptoms of metastatic breast cancer
- All treatments should be individualised to the patient and tumour characteristics and reflect current international standards
- Access to care should be facilitated for hard-to-reach groups (such as those in rural areas, minority ethnic groups, etc.)
- Processes should be in place to speed access to new treatments

The “5 Point Plan”

The elements



Symptoms and side effects should be effectively controlled to enable patients to live a full and active life.

- Clinical trials of new treatments for metastatic breast cancer should include relevant outcome measures, for example quality of life
- Pain and other symptoms should be managed pro-actively
- Fractures should be prevented, and managed effectively to avoid disability if they occur
- Quality of life should be assessed regularly using tools – which may need to be developed - specifically for metastatic breast cancer

The “5 Point Plan”

The elements



Information and support should be accessible and patient-centred

- Psychosocial care should be available for those patients and family members who need it
- Support systems to facilitate daily living should be in place
- Patients should have a written care plan that is updated as circumstances change
- Where available, information about patient groups and peer support programmes should be routinely provided to patients

Metastatic Breast Cancer

Key Facts and Figures

- Metastatic breast cancer is not treatable by primary surgery and is currently considered incurable^[i].
- In developed countries, 1 in 3 women with earlier stages of breast cancer will eventually be diagnosed with metastatic disease^[iii].
- Breast cancer–related deaths are mainly due to the incurable nature of metastatic breast cancer, with a yearly toll of more than 40,000 deaths in the United States alone^[iiii].
- About 25 percent of women with metastatic breast cancer live more than five years after diagnosis^[iv].
- In women who received no treatment for metastatic disease, the average survival from diagnosis of metastases was 12 months^[v].
- Compared with women with earlier stage breast cancer, women living with metastatic breast cancer report feelings of isolation in regard to the attention, support, and care they receive^[vi].

[i] Stebbing J and Ngan S (2010). Breast cancer (metastatic). Clinical Evidence website, women's health section. http://clinicalevidence.bmj.com/ceweb/conditions/woh/0811/0811_background.jsp (Accessed on 16.09.10).

[ii] O'Shaughnessy J. (2005). Extending survival with chemotherapy in metastatic breast cancer. *The Oncologist* 10 (suppl. 3): 20-29.

[iii] Lu J. (2009). Breast Cancer Metastasis: challenges and Opportunities. <http://cancerres.aacrjournals.org/content/69/12/4951.full.pdf+html> (last accessed 12.05pm 20.09.2010)

[iv] Altekruse SF, Kosary CL, Krapcho M, et al. (2009) *SEER Cancer Statistics Review, 1975-2007*. National Cancer Institute, Bethesda, MD.

[v] Cold S, Jensen NV, Brincker H et al. (1993). The influence of chemotherapy on survival after recurrence in breast cancer: a population based study of patients treated in the 1950s, 1960s, and 1970s. *Eur J Cancer* 29A: 1146-1152.

[vi] MBC Advocacy Working Group (2008). Metastatic breast cancer patients: addressing their unmet needs. *Community Oncology* 5 (12): 645-8.

The “5 Point Plan”

Next Steps

- 1. We – at BRO – are happy to receive your comments and suggestions**
- 2. If you would like to receive the “5 Point Plan” please sign off and we will sent it to you**
- 3. Please discuss the “5 Point Plan” with your board and sent us your logo in case you would like to endorse the plan**
- 4. Approximately a month after the Summit we will be producing a revised plan incorporating the logos of al the patient groups who will endorse the plan.**
- 5. We are happy to organize a call in early 2011 in order to discuss and exchange ideas on the implementation of the “5 point plan”.**