

The Breast Care Support Group

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The Breast Care Support Group (BCSG) is a voluntary organisation, set up in the late eighties by a small group of women who had been through the trauma of having breast cancer, and felt that there was not enough support or advice available for women like themselves. Originally the word mastectomy was incorporated into the group title, but as surgery for breast cancer changed, so did the name of the group.

Whilst addressing the needs of women with breast cancer, the group is also involved with supporting women who have had other forms of breast disease. The needs for women who have experienced the psychological trauma of discovering a breast lump

and any subsequent intervention warrants some form of support structure. Whether the lump is benign or malignant, many women who face this distressing situation need help to recover. Although only one in ten breast lumps will be malignant the

other nine still need to be dealt with. The BCSG knows the importance of seeing these cases as ten individual women, as opposed to nine benign breast lumps and one malignant lump. Surgery is not always medically indicated, but the woman herself may decide to go ahead and have the lump removed. This happens because she cannot cope with the doubt she has in her mind as to whether or not she has been correctly diagnosed, or possibly because she may be afraid that if the lump is left it may become malignant. Women are aware that mistakes can be made in diagnosis, and if they live with a breast lump *in situ*, it can cause them to become depressed and anxious. Women need to be better informed about breast disease, and then allowed to decide for themselves whether or not to undergo surgery. The name of the group reflects the involvement with women who have had some intervention related to breast care, not specifically breast cancer. Members of the group are contacted by telephone on a regular basis, to support or to give advice on where to obtain the help or services that they may need.

The BCSG has members in both Malta and Gozo, with monthly meetings being held on both islands. The purpose of these meetings is to give

women the opportunity to meet others who have been through similar experiences. They are given the chance to talk about any problems that they may be experiencing with the nurse advisor to the group, who is trained in Breast Awareness. However this is not all that happens at the meetings! There is a program of educational and recreational activities for these meetings, and some social events are planned each year so that members can include friends and family.

Meetings are held in Malta at the Malta Hospice Movement, which helped the group to originate, and thankfully offers ongoing support to the group. Meetings take place on the first Thursday of every month, morning or afternoon (9:30am to 11:30am and 5:30pm to 7:00pm). In Gozo, the meetings are held at The Cana Headquarters in Victoria, every first Wednesday of the month from 9.00am to 11.00am. An annual fee of Lm3 is charged to BCSG members. Quarterly newsletters are sent out to members.

Apart from this support structure, members of the group reach out to women in other ways. A member of the BCSG visits both public and private hospitals, linking with the nursing staff and consultants. Requests are made for the group to either visit or phone women in need of moral support. This can take place prior to or after surgery and/or other treatment. The role of these volunteers is to offer their moral support and encouragement. These volunteers have guidelines regarding visiting patients; they will not give advice related to treatment, choice of surgeons or discuss their own personal experiences.

A member of the group also offers a free fitting service for prosthesis. The group provides a 'comfy' which is a soft shape that can fit into the bra after surgery, prior to the woman being able to wear the regular prosthesis. This can be a real boost for women leaving hospital, and trying to cope with their altered body image.

The BCSG is aware that both the

public and private sectors do not always ensure that women receive a team approach to care. The service at St. Luke's Hospital has improved a great deal. Areas for improvement, however, include the need for all women to be evaluated by a physiotherapist. Psychological support should be provided when necessary. This applies to women and their partners who may have sexual problems related to the diagnosis and treatment of breast disease. These and other issues will be worked upon in a positive way in the future.

Members of the BCSG give their committee feedback related to their treatment and care, pointing out problems and giving suggestions for improvements. The committee then makes the necessary proposals to the organisations concerned, both within the private and the public sectors.

Education has been a major consideration for this small but effective group. During the last five years educational courses for nurses have been held, and a total of over one hundred nurses have followed a basic breast awareness course, updating their knowledge and giving members of the BCSG the opportunity to form better links with the nursing profession. Breast Awareness Week, allows Health Care Professionals to work along side members of the Breast Care Support Group to promote awareness amongst the general public. This awareness week is held in the last week of October culminating with The Hilda Schembri Memorial Lecture, in memory of one of the founders of the group. Another Breast Awareness Course will be organised later this year, and professionals interested in participating can contact Marianne Micallef on Tel: 2157 2515.

Following meetings with both The Hon. Dr. L. Deguara, Minister for Health and Dr. J. Cachia, Director of Health Institutions, the Breast Care Support Group will be working with a link person from the Department of Health for this year's Breast Awareness

campaign. There have been direct links with the Department of Health for a number of years, but the BCSG had been requesting a link person to work directly with for the past two years, and this is a positive outcome. The Health Promotion Unit is another sector within the Department of Health with which the BCSG enjoys good collaboration. The group, distributes educational Breast Awareness booklets that are available in both Maltese and English, and communicate any feedback in relation to awareness to the Unit. The BCSG has made proposals to Government regarding improvement of the service for women with Breast Cancer. The BCSG has promoted the role of the Breast Care Nurse and the newly established Breast Clinic at St. Luke's Hospital has the services of two part-time Breast Care Nurses. The clinic has a multidisciplinary approach, offering a holistic service to a high percentage of women who present at St. Luke's with a breast lump. The BCSG would be happier if there could be greater involvement between this team and the Oncology Department, which, evidently due to shortage of staff, has no representative at the Breast Clinic team meetings.

The BCSG is in the process of restructuring the committee, and hopes to include some health care professionals, including The Malta Hospice Movement, The College of Family Practitioners and The Commission for the Advancement of Women. This should strengthen the group and help in gaining official recognition from the Department of Health.

The organisation raises funds when there is a specific need, and recently sponsored one of the Breast Care Nurses from St. Luke's Hospital to attend a

The BCSG has a page on the Malta Hospice Movement's Website, which is currently being updated.

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