

Women's day was celebrated and over 3000 pink ribbon "Awareness" pins were given to women employees.

Board members of Europa Donna Cyprus attended the 4th European Cancer Conference in Hamburg where we participated actively in the proceedings.

April included the General Assembly, a seminar by Willie Fourie to physiotherapists on "Late Complications after Mastectomy". At the same time a signature collection was being gathered for the necessity of assuring and ensuring trained nursing staff. Also another awareness talk was organized at Polis, a distant small town of the island.

In *May* we were invited to talk in Ayios Athanasios in Limassol.

In *June* a great event marked our advocacy work – the adoption of the pink silhouettes of Australian Breast Cancer Coalition with a guest speaker the President of the Australian Breast Cancer Network Mrs Lyn Swinburne. The site chosen was by the Presidential Palace.

July followed with the second part of the seminar "Late Complications after Mastectomy" for physiotherapists by Willie Fourie from South Africa.

In *October* awareness week saw our first leaflet on "How to deal with friends and colleagues with Breast Cancer", the illumination in pink of Nicosia Municipality, and the distribution of 200,000 leaflets on general advice on breast cancer through a chain of bakeries. The highlight of the week was the Europa Donna Cyprus first one-day Seminar on "Breast Cancer" by local experts which was attended by over 200 women.

Also in our effort to reach young people we distributed over 50,000 coasters to clubs and cafes.

In *November* a large delegation of the Cyprus Forum attended the Pan European Conference in Rome.

- We now have 1500 members.
- We are preparing 2 new leaflets:
 - 1st – on how to communicate with Children, the facts of breast cancer and
 - 2nd – on advice regarding insurance policies.
- We are organizing meetings with women with breast cancer experience from all over Cyprus.
- We are invited to attend and speak to women all over the island by all sorts of groups.
- We are partners with the Ministry of Health on the best implementation of the screening program.
- We are passionately involved to achieve and offer to women in Cyprus the "BEST POSSIBLE"

The above wording will illustrate along with photos and a map of Cyprus with demographic facts on the work of Europa Donna Cyprus.

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Poster

Providing information and support on all aspects of breast health and breast cancer in Ireland

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In 2001 the Irish Cancer Society launched Action Breast Cancer (ABC) to provide breast cancer information and support. ABC's services are free and include a national helpline, patient education, one-to-one support, health promotion, research, advocacy, and professional support.

Over the last five years, we have been continually developing our services for the public, at the heart of which is the Freephone Helpline. The Helpline is staffed by specialist cancer nurses who offer information, support, and appropriate referral for women who are concerned about breast health, women who have been diagnosed with breast cancer, their families and carers, and healthcare professionals.

In order to meet the need for clear, concise information, we are continually producing and updating literature and supporting materials. This includes a series of factsheets on every aspect of a breast cancer diagnosis including the different aspects of living with the disease.

The Helpline also offers a support programme called Reach to Recovery, which works on the principle of personal contact between the patient and a specially trained volunteer who has had breast cancer.

In January 2005, we launched a programme to address the unique needs of younger women with breast cancer. Services include biannual conferences for younger women, a specialist nurse, and the selection and training of younger Reach to Recovery volunteers.

Professional support is also a key element of ABC's service. Most recently we have developed a workshop for nurses working in oncology to improve communication with breast cancer patients around sexuality.

ABC's annual Breast Cancer Awareness Month campaign takes place in October. A high profile advertising campaign and a nationwide roadshow are just two of the many mediums used to target Irish women in order to make them breast aware for life. Throughout the year, ABC is constantly seeking to raise awareness in communities and workplaces across the country by organising presentations about breast awareness, screening and early detection.

Now that we have firmly established ourselves as the leading provider of breast cancer information and support, we have started to significantly develop our advocacy programme, and we are currently working on ensuring that the national breast screening programme will be fully rolled out by the end of 2007. We are also undertaking major nationwide research into the provision, supply and fitting of breast prostheses.

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Poster

Need for development of guidelines and outcome measures for the management of learning disability patients with breast cancer

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Aim: In England there are 1.2 million people with mild to moderate learning disability (LD) and 210,000 with severe LD (25,000 old people). Women with LD are living longer and are prone to age related diseases such as breast cancer. The likelihood of encountering the learning disabled (LD) with breast cancer is high. Guidelines exist for breast and cervical screening for the LD (1999). Specialized breast units have a need to develop guidelines to manage symptomatic breast cancer patients.

Method: We present our experience in the management of 5 patients with varying degrees of LD diagnosed in 2004–2005. 3 had mild to moderate LD and 2 had severe LD. LD patients were involved in the decision making process and allowed to express their needs and preferences. In the severe LD patient consent to diagnosis and treatment were in the best interests of the patient with consideration into the women's wishes, views from persons who know the patient well. The patient, carer, family, social worker and general practitioner were all involved. Patients were discussed in the multidisciplinary meetings. 2 had mastectomy with axillary clearance + adjuvant hormonal treatment. 1 had mastectomy + axillary clearance and contra lateral breast reduction + chemo and hormonal therapy. 1 had wide local excision + axillary sampling + radiotherapy and adjuvant hormonal therapy. 1 had inflammatory cancer, a course of chemotherapy and refused any further treatment. Patients had support from the breast care nurse in the hospital and at home as and when required. Complementary therapies were also offered to patients.

Discussion: LD patients should be encouraged to utilize the screening programme and seek help when they have a symptom. Health service should be easily accessible and extra support provided. They should be given adequate time. There should be information leaflets specifically designed for the LD for every stage of the management process. Family/carers of the LD should also have access to information and support. There should be required support when LD patients are admitted into hospitals for surgery. Patient centered care must be provided.

Conclusion: The health care needs of LD people must be met and be delivered to a high standard. Health professionals involved in the management of LD patients should have training in dealing with these patients. Outcome measure of the health status of the LD should be comparable to that of the general population. Hence guidelines and outcome measures for management of LD patients with breast cancer need to be developed.

Wednesday, 22 March 2006

16:00–16:45

POSTER SESSION

Psychosocial aspects

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Poster

5-year follow-up of sexual functioning and sexual enjoyment after radiotherapy for early stage breast cancer in the START trial

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Introduction: Long-term QL for women with early breast cancer is being systematically investigated in the START trial. This analysis examines self-reported sexual functioning (SEF) and sexual enjoyment (SEE) following surgery +/- chemotherapy, and after radiotherapy (RT), over 5 years follow-up, irrespective of the radiotherapy schedule received.

Methods: QL was evaluated in 2180 patients (mean age 56.5, range 26–86) using EORTC BR23, 10-item Body Image Scale (BIS) and 14-item HADS prior to and 6, 12, and 24 and 60 months after RT. Three BR23 items assessed SEF/SEE. Spearman correlation coefficients were evaluated

between SEF and SEE. Predictors of change over time including age, clinical and psychological factors, were examined using multiple regression and the population average GEE model.

Results: At baseline, 2087 women completed the SEF items, of whom 56% reported that they lacked interest in sex, and 40.6% women were sexually active. SEF and SEE were correlated over all time points ($r = 0.5-0.66$) but SEE scores were generally low. Proportions of women reporting 'a little', 'quite a bit' or 'very much' SEE were 34%, 39% and 22% respectively. Older age, CT and HADS anxiety and depression were significantly associated with worse baseline SEF/SEE with no effect of type of surgery, time since surgery, endocrine therapy or body image (BI). SEF improved significantly from baseline to 6 months ($p < 0.001$) but thereafter declined up to 60 months ($P < 0.001$) towards baseline levels. Psychological variables affecting decreased SEF were poorer body image and increased HADS depression and anxiety. Age greatly impacted SEF with patients ≥ 50 years (proxy for post-menopausal status) reporting significantly worse SEF compared to those aged < 50 ($p < 0.001$). There was a steady decrease of SEE over time from 0-60 months with similar variables affecting this change, except for HADS anxiety, which was not significant.

Conclusion: Although CT has an initial adverse effect, sexual functioning and enjoyment appear to be mainly affected by age and psychological variables over time. The observed associations with depression and body image warrant further investigation and results will be reported. Women should be informed of likely treatment effects and offered appropriate advice and support.

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Poster

Factors affecting body image concerns in early breast cancer

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Introduction: To explore the contribution of age, clinical and psychological factors on body image concerns, in women with early breast cancer treated in the START trial. This is a UK multicentre randomised trial of adjuvant radiotherapy in which quality of life will be an important secondary endpoint.

Methods: Women participating in the quality of life (QL) sub-study completed the 10-item Body Image Scale (BIS) and 14-item HADS, together with other standardised QOL measures, at baseline (after surgery and adjuvant chemotherapy but before radiotherapy) and at 6, 12, and 24 and 60 months follow-up. At baseline, the independent effects of age, clinical factors (time from surgery, type of surgery, chemotherapy, endocrine therapy), depression and anxiety were identified using multiple regression analysis. Change over time was tested using the Generalised Estimating Equations model.

Results: 2181 (99%) women completed baseline QL questionnaires, (mean age 56.9 years, range 26-87). 17.1% women had mastectomy, 82.9% underwent conservative surgery; median time from surgery was 8.0 weeks (IQR 5.6-19.6). One third of patients received adjuvant chemotherapy (CT). 75% women reported BIS concerns of any severity at baseline; the most prevalent body image items rated as 'quite a bit' or 'very much' were '... feeling less physically attractive', '... feeling less sexually attractive', '... feeling less feminine' and '... dissatisfied with your body'. Significantly worse BIS summary scores ($p < 0.001$) at baseline were found for women of younger age, having mastectomy, and/or receiving chemotherapy. BIS scores improved significantly from baseline to 1 year ($p < 0.001$) and were stable from 1-5 years ($p = NS$). There was no apparent negative effect on BIS scores from radiotherapy or endocrine therapy. From 0-12 months, poorer body image was predicted by age, having mastectomy, receiving chemotherapy, and greater anxiety and depression; these factors also predicted the most prevalent body image concerns. CT had no further effect from 12-60 months but the other factors remained.

Conclusions: Overall body image concerns improve over time and whilst the impact of CT remits after one year, the negative effects of age, mastectomy, anxiety and depression persist. A subgroup of patients at risk of body image disturbance can thus be identified. Neither radiotherapy nor endocrine therapy appear to have an influence on body image scores.

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Poster

Patients' views of distress and interference with daily activities due to side effects from chemotherapy for early breast cancer: the TACT (Taxotere as Adjuvant ChemoTherapy) trial experience

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Introduction: 4162 women with early breast cancer were randomised to receive adjuvant chemotherapy (CT) in the TACT trial (FECx4 followed by taxotere x4; (FEC-T)) vs FECx8 or epirubicin x4 + CMFx4 (E-CMF)) in which Quality of Life (QL) is an important secondary endpoint. This analysis describes the patient experience of chemotherapy side effects from treatment, in terms of distress and interference with activities, rather than just severity.

Methods: A protocol specific measure of 15 toxicities in the form of a daily diary card (not reported) and two additional questions, relating to *distress due to side effects* and extent of *interference in daily activities* from side effects was requested from all patients in the QL study. Questions were completed during CT (cycles 1, 5, and 8) and at 9, 12, 18 & 24 months. Patients rated *distress* and *interference* for each toxicity as 'not at all', 'a little', 'quite a bit', 'very much'. Toxicities rated as *distressing* or *interfering* with day to day activities (quite a bit/very much) by $>10\%$ patients at each time point were collated.

Results: Toxicity questions were completed by 455, 468, 410, 667, 645, 604 & 576 patients at cycle 1, 5 & 8 and at 9, 12, 18 & 24 months respectively. In cycle 1, *distressing* effects were nausea, vomiting, tiredness and constipation, reported by 30.4%, 20.1%, 30% and 13% patients respectively. Nausea, vomiting and tiredness also *interfered* with daily activities in similar proportions of patients. During successive cycles, most (12/15) symptoms were reported as *distressing*, with the exception of vomiting, skin problems, and lack of appetite. Symptoms most likely to *interfere* with activities on CT were nausea, tiredness, sore mouth, breathlessness, pain in muscles/joints and painful/gritty eyes, affecting 13%-54% patients, with greatest increases for breathlessness and painful muscles/joints. Following CT, only tiredness and pain in muscles/joints were reported as *interfering* by $>10\%$ patients but persisted up to 2 years from baseline. Over 10% of patients reported *distress* due to skin problems, tingling hands/feet, swollen hands/feet, nail changes, tiredness and painful muscles/joints at some point following treatment, with the latter two persisting for up to 2 years.

Conclusion: Most CT side effects cause more distress than interference with daily activities. Whilst most functional effects reduce over time, distress may persist for up to 2 years post CT and warrants more attention from treating teams.

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Poster

The psychological impact of regular surveillance in women at increased risk for hereditary breast cancer

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Aim To identify women at risk for hereditary breast cancer adhering to regular surveillance who experience increased distress.

Methods 357 High-risk women (cumulative life time risk $>15\%$) participating in the psychological sub-study of the national MRISC-study, regarding the evaluation of MRI-screening in high-risk women were studied. Questionnaires, administered before and after two surveillance-visits (C1, C2), assessed the psychological impact of adhering to the surveillance programme (annual MRI and mammography, biannual clinical breast examination). Outcome variables were BC specific distress (Impacts of Event Scale) and general distress (Hospital Anxiety and Depression Scale). With regression analyses and Structural Equation Modelling subgroups of women who were vulnerable for psychological distress and the courses of distress around surveillance were explored.

Results At baseline (i.e. two months before the surveillance visit) three factors were found to be associated with higher levels of BC specific distress: excessive breast self examination while being younger than 40 years of age; risk overestimation (cognitive and affective), and being