



# EONS newsletter

The Quarterly Newsletter of the European Oncology Nursing Society

Fall 2005

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## ECCO XIII, Paris



# Colofon

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The goal of the EONS Newsletter is to inform nurses about EONS and its activities and to provide a forum for cancer nurses throughout Europe to network. The information published in the EONS Newsletter is intended to inspire nurses to improve the care of the cancer patient through improved knowledge.

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# Letter from the Editor

## Welcome to the Fall issue of the EONS Newsletter!

A lot of people have ideas that can be realized to improve cancer nursing practice. Not everyone has the ambition, courage, or energy to let their ideas become reality. When someone does, it often makes a difference; for the patients on a single ward or for colleagues at a department, or, in the best of worlds, sometimes even for an entire hospital. I wonder how many cancer patients and significant others in Europe have been helped to better cope through the program 'Learning to live with cancer'. They can all thank Dr. Gertrud Grahn for that. She heard about Judi Johnson, an American cancer nursing educator and researcher, and her work with the program 'I can cope' in the United States during the 1980's. Dr Grahn adjusted the program to better suit the European culture and introduced the program first in Sweden and then in the rest of Europe. Many nurses from all over Europe

have taken part in arranging train the trainer courses to become leaders of 'Learning to live with cancer'. They have helped thousands of patients and their relatives to a better life during and after the cancer journey. Gertrud Grahn's work has made a difference in clinical practice! When I heard the sad news about her death, a celebration of her work in this issue had already been planned. It is sad that she can't read it herself! We all need to promise to keep up her fantastic work in the future. In honour of Gertrud, we should never stop trying to improve clinical cancer care!

In this issue, is a clinical paper regarding symptom management of cancer related symptoms. The focus for the paper is the importance of identifying barriers for optimal management. Read it, take a look at risk factors at your own working place, and do something about it!

Karin Ahlberg, Editor in Chief

# EONS News

## Accreditation Update

The Accreditation Council is pleased to announce that the following courses have been granted EONS accreditation:

10<sup>th</sup> International Seminar: Palliative care of patients with cancer (Palliativbetreuung von Tumorkranken). This is a short course, offered in German and presented by the European School of Oncology, German Division.

9<sup>th</sup> International Seminar: Advanced cancer nursing (Onkologische Krankenpflege: Fortgeschrittene Praxis). This is a short course, offered in German and presented by the European School of Oncology, German Division.

Ecole d'Ergologie de Belgique, Soins Infirmiers spécialisés en Oncologie, Institut Jules Bordet, Brussels, longer course, October 2005 - June 2006

For more information contact: EONS at  
www.cancerworld.org

**Did you know?**

You can upgrade your EONS membership on renewal to include the European Journal of Oncology Nursing. At a cost of only EUR69/EAN, your society membership brings you four issues of EJON per year - including full text electronic access!

Contact the EONS secretariat office to take advantage of this offer, details in the bi-monthly subscription

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[intl.elsevierhealth.com/journals/ejon](http://intl.elsevierhealth.com/journals/ejon)

## Honorary Membership Awarded to Two Outstanding Nurses

EONS President, Jan Foubert, is pleased to announce the awarding of honorary EONS memberships to **Kathy Redmond** and **Mary Uhlenhopp**. Kathy, a Past-president of the Society currently working as a nurse consultant, was selected due to her steadfast commitment to open doors for EONS involvement in European projects. Kathy has been tireless in her efforts to promote EONS at a European level and to promote communication between the Society and patient advocacy groups. Mary Uhlenhopp, Clinical Education Manager at Amgen, Europe, received the honour based on her efforts to put EONS on the agenda at



the industry (pharmaceutical) level. She has demonstrated loyalty to EONS through her efforts to provide support through unrestricted educational grants. Both Kathy and Mary were instrumental in the development and initiation of the successful TITAN project.



Honorary membership may be conferred on individuals in recognition of their distinguished contribution to cancer nursing. The individual receives a free EONS life-time membership. Past-president Agnes Glaus is also an EONS Honorary Member.

## Our colleagues from... France

### The History of the Society

The French Society for Nurses in Cancer Care (AFIC Association Française des Infirmier(e)s de Cancérologie) was created in 1981 on behalf of nurses who wanted to promote the profession and training of nurses in cancer care. The publication of the official newspaper of the Society in September 1981 provided AFIC with a legal existence. This important event was made possible by a contest sponsored by the National Cancer League who was interested in assisting nurses active in cancer care to establish a formal organisation. The grounding of AFIC was officially announced during the 1st European Congress on Care in Oncology held in Lausanne in October 1981.

### The Goals of the Society

The AFIC participates in the evolution of knowledge in cancer care through the development of a network of professionals with many complementary competences. The goals of the Society are:

- The formal organisation of nurses caring for cancer patients
- Development and promotion of knowledge in cancer care
- Foster collaboration between nurses practicing in different settings
- Provide training of nurses
- Develop collaboration with other national and international societies having the same aims.

### The Structure of the Society

The Board is composed of 9 active members who meet every 6 weeks in Paris at the head office of the National Cancer League. Each member of the Board has a particular mission:

The President and Co-treasurer is Pascale Dielenseger, the Treasurer and Vice-president is Frédérique De Hoorne, the Secretary and representative of the project "Vie en couleur and Eliots is Nicole Hubert, the Chief Editor of the BIC (Bulletin Infirmier du cancer/ the oncology nursing newsletter) and Vice-president is Véronique Frauche, the representative of nurses in home care and expert in enterostomatherapy is Eliane Toureille, the representative of nursing schools is Clotilde Messin, Sarah Brun is responsible for the Society's website, the expert in enterostomatherapy and wound healing is Nicole Rama, and Françoise Charnay-Sonnek is the Society's representative to EONS.

### Benefits for Members

Efforts are made to encourage members of AFIC to share their knowledge and experiences. They can

enrich their competences in cancer care at national and international levels and they can obtain grants for conferences in cancer healthcare. Members can access special sections of the Society's website which are reserved for members only. Last but not least, we welcome members to publish articles in the Society's newsletter, BIC.

### Collaboration with Other Organisations

Since the creation of AFIC, the National Cancer League has been its most faithful partner.

The pharmaceutical firms who kindly sponsor the RIO (Rencontres Infirmières en Oncologie), a congress for nurses in cancer care, are also valuable partners of the Society. The RIO, first organised in 1997, is held every year in Paris in collaboration with Tutti Frutti, a communications company. Approximately 600 participants attended our congress in 2005.

The national and international societies, with whom the AFIC is affiliated include the ISNCC, UICC, ESO, EONS, EORTC, SIO (Société des Infirmières de Belgique), and the Quebec Nurses Society (Société des Infirmières Québécoises). In addition, the AFIC has a close collaboration with all French-language general nursing journals.

### Suggestions for Future Collaboration with EONS

Continued collaboration with EONS is surely one important aim of AFIC. We are fully aware that the exchange of knowledge with other European countries and collaborative work on evidence based nursing practices will be the basis of the profession of nursing in the future. Nevertheless, language barriers are still a major handicap to achieving true collaboration with our European colleagues. Unfortunately, only a small number of French nurses speak English. Certainly, this situation is changing, but it will take a long time until the majority of French nurses can communicate in English at a level which will allow them to network in a mutually-satisfying way with English-speaking colleagues. The AFIC does not have the power to influence the Nursing Formation Institutes to include English lectures in their teaching concepts. Therefore, the translation of important projects of EONS and of the EONS Newsletter into French is of great assistance in providing collaboration between AFIC and EONS. In turn, translation helps to promote the image of AFIC in France and other French-speaking countries.

# L'AFIC



Association  
Française  
Infirmier(e)s de  
Cancérologie

# Gertrud Grahn

## In Memoriam



Tore Kr. Schjølberg  
Assistant Professor, Oslo University College, Norway

Dr. Gertrud Grahn, known to many in the EONS-community, died 22. July 2005. Gertrud was born in Malmö, Sweden in 1930. Most of her professional life was dedicated to nursing education. She received her PhD in Education from the University of Uppsala in 1987. The title of her doctoral theses was: *“Educational situations in clinical settings. A process analysis”*. Following the completion of her PhD, Gertrud moved to Lund, Sweden and worked as a senior lecturer and director of the health care research unit until she retired from her post as Associate Professor in 1995.

To most of us, Gertrud was known as a very enthusiastic and well-informed cancer nursing educator and an exceptional source of inspiration. She developed and implemented the programme *“Learning to live with cancer”*, a programme which is now implemented in 15 European countries.

Gertrud’s contribution to cancer nursing both in Scandinavia and abroad was well known. She served on the Editorial Board of several scientific journals including *Cancer Nursing*, *the European Journal of Cancer Care*, *the Scandinavian Journal of Caring Sciences* and *the Journal of Cancer Education*. In addition, she served on numerous national and international commissions. She was heavily involved with EONS. She served on the Academic Committee of the European College of Cancer Care and she was also involved in the EC-EONS working group on developing a Core Curriculum for a Post-basic Course in Cancer Nursing in Europe. She also served on the scientific committee for several ECCO conferences. Gertrud’s enthusiasm for cancer nursing went beyond the boundaries of Europe: she served on the Board of Directors for the International Society of Nurses in Cancer Care (ISNCC), on the Advisory Council

of the International School for Cancer Care and on the WHO-CIOMS Committee on Ethics and Research.

For her tremendous contribution to cancer nursing education, Gertrud was the recipient of the EONS Distinguished Merit Award in 1995. Her achievements included research in patient education, psycho-social aspects of patient care, nursing education and palliative care. The results of her research have been widely published and presented at conferences all over the world. Based on the *“Learning to live with cancer programme”*, she developed and implemented an educational programme on caring for patients with dementia.

After Gertrud retired, she moved from Lund down to the coastline of southern Sweden. Being close to the sea was important to Gertrud. She got inspiration from the water and much of her reflective work was done overlooking the sea. Her life did not slow down with retirement. Gertrud loved to travel and only weeks before she died she visited the New Opera House in Copenhagen and travelled to Switzerland on business. Fortunately, her medical condition did not stop her from doing what she wanted to do. An anecdote told by one of Gertrud’s old friends at her funeral provided insight into her life. *“Gertrud would never ask for an easier burden, she would rather ask for a stronger back”*.

For all of us who were fortunate to know Gertrud, she will be heavily missed both as a good friend and as a role-model. Our thoughts are extended to her daughter, Eva, and her grandchild, Bodil, who have lost their loved one.

# History of a Legend:



## Learning to Live with Cancer Program

Carol Krcmar, EONS Editorial Team

In a fast-changing field such as cancer, it's hard to imagine that an initiative developed 20 years ago is still in practice. Not only does the 'Learning to live with cancer' program continue to be offered, but it's concept and content are still of relevance. In honour of Gertrud Grahn, founder of the 'Learning to live with cancer' program, this issue of the EONS Newsletter highlights her life's work; a result of which was the empowerment of cancer patients and their families through the provision of education and support.

### From Research to Implementation

As early as 1985, Judi Johnson, an American cancer nursing educator and researcher, conducted studies on patient education. Her studies resulted in the development of the "I can cope" patient-directed program which was promoted by the American Cancer Society. Gertrud Grahn was researching the topic of patient education in Sweden at the same time. During Judi's term as Visiting Professor at the Care Research Unit, Lund University in 1987, the two collaborated to plan the 'Learning to live with cancer' program. As the first phase of the research project, a learning-needs assessment and analysis was carried out in 1988 to identify the needs of cancer patients and their family members. Based on the results of this first phase, a structured program comprising 16 hours of education was developed in collaboration with patients and family members/significant others from 1988-1991. In the evaluation phase conducted between 1990 and 1992, 127 program participants were asked to evaluate the program and the learning materials.

In 1992, the 'Learning to live with cancer' program was offered to cancer patients and their families in Sweden. At first, 4 courses per year were offered with an average of 20 persons participating in each course. Due to the success of the program, it soon became evident that additional leaders would be needed to implement the course on a country-wide basis. Hence began the 'Training the Trainers' initiative to prepare nurses, doctors, social workers, occupational therapists, and physiotherapists to provide group-education for cancer patients and their significant others. Translation of the program and learning materials into Norwegian followed in 1995 with support provided by the Norwegian Cancer Society.

Gertrud's conviction of the benefits of the course led to its dissemination throughout Europe. The European Union's 'Europe against Cancer' program allocated money for this purpose. The first European workshop with participants from five different European countries was held in Sweden in 1995. Participants from Ireland, Scotland, Italy, Belgium, and Estonia attended. In 1966, courses were offered in Dublin, Milano, Leuven and later in Glasgow.

### Concept of the Program

'Learning to live with cancer' is a structured education and support program for cancer patients and their families that aims to inform them about cancer and to help them understand what is happening to them. Taking place over eight 2-hour sessions, the program provides support, opportunities to exchange information and to share experiences with others. The course enables people to develop coping strategies and instils confidence, hope and optimism to help them live more fully despite their cancer.

In order to strengthen the impact of the program, it became necessary to specially train health care professionals to implement content. 'Training the Trainers' workshops, which last 5 days, are aimed at training nurses and other health care professionals to become course leaders with competence to run patient/family group education. Workshop content is designed to build on the information-giving expertise of health care professionals to enable them to use educational work and the information it communicates as a coping strategy for their patients.

Trained health care professionals who had experience conducting courses

were then eligible to themselves conduct 'Training the Trainer' workshops. Although quite simple in concept, through a multiplication effect, properly prepared and experienced course leaders passed their knowledge on to others who continued the process thus providing a vast network of leaders who could offer patients a program of high quality.

### EONS Involvement

EONS, with funding provided by Bristol-Myers Squibb, facilitated the further development of the 'Learning to live with cancer' program in 12 countries in Europe. Through the EONS membership, interested and qualified nurses to participate in the 'Training the trainers' workshops were identified. An important outcome of EONS's involvement was the procurement of funding to translate the program materials into several languages thus enhancing dissemination. As early as 1999, the 'Learning to live with cancer' program was being conducted in 10 European countries.

EONS involvement in the dissemination of the program helped to ensure a quality-control of the preparation of course leaders, the possibility to track where the program was being offered, and a means of conducting proper evaluation. Due to a number of circumstances, the collaboration between EONS, Gertrud Grahn and Bristol-Myers-Squibb in promoting the program came to an end in early 2000.

In conclusion, patients and families who have participated in the program have consistently evaluated it positively. The 'Learning to live with cancer' program proved to be flexible enough to meet the learning needs of patients in different cultures. Continual development of the program based on evaluation is important: the learning needs of patients and their attitudes toward cancer change and the course content should reflect these changes.

It's hard to now believe that a pre-requisite for participation in the program was that patients were told the truth about their diagnosis. Sometimes it seems as though patients are being bombarded from every direction with information on their disease and treatment and that they can't possibly absorb any more input. While a major aim of the 'Learning to live with cancer' program was to provide education, it was the exemplary training of the course leaders and the opportunity for patients to learn coping strategies from them as well as from fellow patients that made participation in the program a personally enriching experience for all involved.



Swiss brochures of the "Learning to Live with Cancer" program

# Learning to Live with Cancer



*Kicki Klaeson, RN, MPH  
Surgery Clinic, Oncology Department  
Lidköping Hospital, Sweden*

## Personal Reflections on the Program

In 1992 when I first heard about the program "Learning to Live with Cancer", I was studying oncology in Stockholm at the Karolinska University. Gertrud Grahn was invited to speak about the program which was new and not yet implemented into practice in Sweden. The program sounded fantastic – an educational program that also addressed the needs of relatives! Two years later, I had the opportunity to join the program and start a local course together with a social worker with whom I was working. We had a great time as course leaders. Gertrud was obviously a leader who taught us tremendous skills on how to use the material she already had produced in collaboration with cancer patients and their spouses. From 1995 to 2000 we held eight courses in Lidköping, a small town in the southern part of Sweden. In total, 160 patients and their relatives, the youngest 14 years old, participated in the Learning to Live with Cancer program and they were all very satisfied. During the years that the course was being offered, we were often told from other members of the health care team that they were able to identify those patients who had participated in the program. Those who had participated possessed better skills and more self-confidence to act and take an active part in their own rehabilitation and treatment options.

For my colleague and me, leading the course was a new challenge which provided us with a unique experience. We both matured personally and professionally. As a nurse, the skills I developed from being a course leader proved to be an asset to me in all aspects of my work. Unfortunately, the course is no longer being offered and there are many reasons why we haven't been able to continue. One reason for the discontinuation was, of course, a lack of financial support. Another is the fact that being a course leader and working on a busy cancer ward was very exhausting for me. As an alternative, we offer our patients the opportunity to join our rehabilitation program. Ten times during spring and autumn, patients can receive physical training in a warm water pool together with other patients under cancer treatment. Sometimes during these rehabilitation sessions we offer patients lectures on different topics that we feel are of relevance for them. The aims of these lectures and the organization of the course are in line with the concept of the Learning to Live with Cancer program. The spontaneous interaction that often occurs between participants is a successful way of learning to cope with a new life situation. We also continue to learn from our contact with these patients and can use these experiences to help other patients cope with cancer.

# Learning to Live with Cancer



## 10 years of practice in the Republic of Ireland

*Ursula M. Courtney R.G.N., M.Med.Sc.*

In March 1995, the Irish Association of Nurses in Oncology (I.A.N.O.) sent me as a participant to the inaugural European Training the Trainers programme to be held in Lund, Sweden. The area of patient education was developing in Ireland and the provision of good patient and family education and support was a challenge for nurses. The Republic of Ireland has a population of 3.9 million people of whom about 20,000 are diagnosed with cancer each year. Ten years later, it is a very fitting tribute to the late Dr Gertrud Grahn to look back at the progress of 'Learning to live with cancer' in Ireland in relation to participants and facilitators and to explore its position in the area of cancer patient and family education and support.

Following the training course in Lund, 1996 saw the introduction of the "Learning to Live with Cancer"® programme to an Irish audience. The inaugural programme was in ARC Cancer Support Centre, Dublin, in February 1996. This was a very exciting time to introduce such a programme as it coincided with the opening of ARC House, the first of its kind in Ireland. ARC House is a beautifully restored Georgian home whose refurbishments were undertaken with great care to ensure that ARC would be a place of beauty and tranquility while also creating a sense of peace and healing within the House. Standing for Aftercare Research Counselling, ARC Cancer Support Centre is a voluntary organisation and registered charity. ARC House offers support to people affected by cancer and those who care about them. The support is holistic and complements the primary medical treatment with education and psychological care. Consequently, "Learning to Live with Cancer"® would lay the foundations for future education programmes within ARC House.

Those who attend ARC are people diagnosed with cancer, adult family members and friends affected by cancer as well as members of the caring professions who work with people with cancer. Subsequently this meant that ARC was an ideal venue to offer the programme as it would reach out to all those to whom the programme is intended. In addition, ARC clients come

from all over the country and it was thought that varied individual experiences would lend an added dimension to the programme.

The first programme commenced with twenty-eight people and was hugely successful. The evaluations demonstrated the need to continue to offer such a course and also demonstrated that this programme should be offered in cancer treatment centres throughout the country.

The last international training programme for the Training the Trainers was held in Dublin in April 1997. While this Training the Trainers was in progress, so also was the third "Learning to Live with Cancer"® programme in ARC House. Dr Gertrud Grahn came to listen to and speak with the participants of the programme. She heard first-hand from this group how worthwhile they were finding the programme and how their educational and psychological needs were being met in a very non-threatening manner. She felt it was an honour for her to hear the open and honest views of this Irish population.

The I.A.N.O. received many requests from nurses wishing to complete the training course with a view to setting up the programme countrywide. Due to this demand, three national Training the Trainers courses have taken place in Ireland. The first was in March 2000, the second in February 2002 (which included two Icelandic representatives!) and the most recent Training the Trainers course took place in February 2004. Consequently, since 1995, a total of 62 people in Ireland have completed the training course. Financial support and sponsorship for the national courses was generously donated by the Department of Health, Irish Cancer Society, the I.A.N.O. and Bristol Myers Squibb, Ireland. In addition, we were privileged to have Dr Gertrud Grahn at each of the courses. Her enthusiasm and wisdom added so much to the week.

In November 2004 it was agreed that a sub-committee of the I.A.N.O. should review the role of the programme in Ireland and explore possible problems being experienced by facilitators. There was awareness that problems existed in areas of the country where the programme was not being implemented.

Resulting from a meeting of the commissioned sub-committee, a survey was conducted in April 2005 to update the database of facilitators and explore issues people might be having with a "Learning to Live with Cancer"® programme. Over a ten year period, almost one-third of the trained facilitators had left oncology nursing, others had moved to live and work overseas and some had retired from nursing.

A questionnaire was sent to forty-four people who had completed the national training courses. Twenty-eight replies were received. The results indicated that six people had not run a course for a wide variety of reasons. As the largest population is situated in Dublin, most "Learning to Live with Cancer"® programmes take place here. Only three venues outside Dublin have facilitated courses, despite the fact that participants for the national Training the Trainers programmes had been selected to ensure an even

spread of the programme throughout the country. A total of fifty-four "Learning to Live with Cancer"® programmes had been organised and facilitated throughout Ireland. The number of participants varies greatly from one course to another and from one venue to another. All problems associated with facilitating the programmes are currently under review by the sub-committee of the I.A.N.O.

In conclusion, the "Learning to Live with Cancer"® programme in Ireland is a very successful educational intervention for people who have been affected by cancer. Several hundred people each year have benefited greatly from this programme. Facilitating a course offers a unique sense of satisfaction of a job well done. Gertrud Grahn has left a wonderful legacy to so many people all over Europe, a very great achievement by one very determined woman. It was an honour to know her. Thank you Gertud—may you rest in peace.

## Learning to Live with Cancer



### The Swedish Experience

*Andrea Magnusson, RN  
KVH-Fenix Center for Rehabilitation and Psychosocial Support  
Kristianstad, Sweden*

"Learning to live with cancer" (LLC) is an excellent example of evidence-based knowledge. This successful programme shows how clinical research can contribute to improving cancer care. Almost 6000 patients and their significant others have participated in the LLC programme since it was initiated 16 years ago. LLC is run by 150 trained course-leaders and is currently being offered at 35 different locations in Sweden. At some larger hospitals, one can even find the programme being run in several departments, for example the departments of urology, neurology and of course oncology and haematology.

Why has this education and support programme been such a success? In my opinion, there are at least 4 reasons that have contributed to the success of LLC in Sweden:

- The main reason is that the programme has a patient perspective; it was designed from the results of a learning needs-assessment. Respect for the patient's autonomy and uniqueness was a key mark for the work of Gertrud Grahn. She was in close cooperation with both patients and their significant others when developing the programme. The learning materials reflect the life situation of patients and their families.
- Cancer is in a way a "family disease"; it impacts on so many people and it is therefore important that the programme involves not only the patient but also family and friends. The purpose of the programme is to help participants to gain coping-strategies through knowledge, different kinds of exercises, and through meeting other people in a similar situation.
- To be able to spread the programme throughout Sweden, Gertrud developed a "train the trainers' course". Ten years ago, she and her team educated the first European course-leaders with funds from the European Union's "Europe against cancer" programme and Bristol Myers Squibb. Since then, hundreds of teams have been educated in Sweden. The team members are mainly nurses and social workers but also doctors, physiotherapists and others. As a course leader, one soon recognizes that running a course is a mutual learning situation. One meets the patient and their family in a totally different way compared to traditional situations in health systems.
- The success of LLC also depends on course evaluations. These evaluations make it possible for course leaders to recognize the special needs in the current group and to be flexible within the frame of the programme to meet these needs.

In Sweden, there is a small steering-group responsible for several tasks such as securing the quality of the programme, keeping in touch with course leaders, and receiving new ideas from patients and family members. Once every year, a two-day meeting is held. Course leaders from all over Sweden meet to listen to lectures and update their knowledge in cancer treatment and care. We also have discussions regarding re-developing the programme in response to comments from patients' evaluations. As a result of patient input, two new themes have been added to the programme, fatigue and pain treatment. During 2005, all the learning material will be audited to update both layout and the presentation of medical facts.

One difficulty in Sweden is the lack of a nation-wide organisation responsible for LLC. In Norway and Finland, the programme is run by the cancer society. In Sweden, each hospital organises and financially supports its own programme which means that they are at constant risk of losing funds to run the programme due to budgetary cuts.

Gertrud Grahn's research showed that anxiety of the patient and relatives is decreased through the LLC-programme. Their self-confidence is increased as they discover and learn new coping tools. Now it is time to find standards to measure what the health economic gains are as is similarly practice in the fields of pain treatment and patient education. Important issues like patient compliance, patient and relatives use of sick-leave, frequency of contacts with the health system etc., need to be assessed. Another interesting theme is to gather knowledge about teenagers who are close relatives, their need for support and information and how a LLC-programme could be developed to best suit their particular needs.

A way of strengthening the programme in the future could perhaps be that course leaders through EONS start a 'LLC Special Interest Group' the purpose of which would be to guarantee the quality of the programme in different European countries. As Gertrud once stated "a similar programme at many different places in the same country will have a greater impact and make it easier to integrate patient education in the care provided for cancer patients and their significant others".

*Ann E. Murphy,  
RN, Bachelor of Education, Oncology Division,  
University Hospital of Geneva, Switzerland*

## A Report on the Swiss Experience

In 1996 and 1997, three Swiss nurses were given the opportunity to participate in the EONS 'Training the Trainers' workshop for the Learning to Live with Cancer program. In the German part of Switzerland, one nurse went to the training held in Athens in 1996, and 2 nurses from Geneva (French-speaking part) to Dublin in 1997. All three nurses had been working in oncology for several years and two of them had experience in patient education and patient support groups.

As a result of the training, the Learning to Live with Cancer program was started in Bern and Geneva in 1998 and since then the program has constantly developed in Switzerland to the point that now 10 to 20 groups are running in several different locations. Unfortunately, until now, it has not been possible to offer the program in the Italian part of Switzerland, although it has been presented to nurses there and has generated great interest. Actually, we can say that more than 600 patients and family members have participated in Learning to Live with Cancer in the German and French parts of Switzerland to date.

A great variation in the number of participants has been observed. Generally, more than 20 people participate in the program in smaller towns where information sources or support groups are not common. In contrast, the average number of participants is lower in larger towns like Geneva where psycho-social support is well developed.

The groups meet in hospitals, clinics, regional cancer leagues or even in private facilities. A fee is charged to participants and course leaders and teachers are generally paid for their work as meetings often take place in the evenings and not during normal working hours. In Switzerland, each group receives financial support from institutions, the regional cancer league, pharmaceutical industries or private donations. Bristol Myers Squibb Switzerland has been involved mainly in the Training the Trainers courses and has provided support for printing booklets until 2003. Several pharmaceutical companies have been approached and have positively responded, in particular Roche, to become involved in the training workshops. Since January 2005, Amgen has been the main sponsor for the program in Switzerland. The Swiss Oncology Nursing Association has been involved in informing members about the program and the Training the Trainers initiatives and in distributing educational materials. The program was presented at the national meeting in 2005 and articles have been published in the association's newsletter.

The success of the Learning to Live with Cancer program has been made possible through the organisation of Training the Trainers workshops both in



*Multi-lingual educational material for the "Learning to Live with Cancer" program in Switzerland*

French and German. French-language workshops took place in 2000, 2002 and 2004, and German-language workshops in 2002 and 2005, representing a total number of 67 persons trained. Fortunately, Gertrud Grahn was able to participate in all these workshops thus providing direct contact with the initiator of the program which was positively evaluated by all participants.

Although there were not always two nurses from the same hospitals trained as leaders as recommended by Gertrud Grahn, all the nurses trained were members of the Swiss Oncology Nursing Association. Some of the participants were students in post-graduate oncology specialisation courses in which the Learning to Live with Cancer program was one of ten modules. Validation of this patient education module included starting a new group with patients and families or participating in an existing one. This system has strengthened and helped to disseminate the program. It also provided fantastic input into the quality of the program and encouraged networking of program trainers. The networking has evolved into an association of trainers who meet once a year. At their annual meeting in 2002, the members formed the "Swiss Association Learning to Live with Cancer®" which has the following aims:

1. Encourage the organisation of Learning to Live with Cancer groups in Switzerland;
2. Train trainers for the program;
3. Supervise and support persons who have been trained;
4. Constitute a place of exchange of information and a link between trainees and people interested by the Learning to Live with Cancer program;
5. Evaluate the program with a view towards its continued development;
6. Promote the Learning to Live with Cancer Program;
7. Facilitate the management of financial resources;
8. Maintain links with other associations pursuing the same goals.

In order to reach these goals, the association organises regular workshops and supports trainers through a structure of coaching for every new group. Further, the association has designated regional supervision for on-going groups. Annual meetings for exchanges are organised both in French and German and facilitate links between course leaders. The association also looks for potential sources for funding the program.

Exchanges also take place through an internet site which publishes general information on the program. The site has pages designed for professionals as well as pages for patients and families ([www.apprendre-à-vivre-le-cancer.ch](http://www.apprendre-à-vivre-le-cancer.ch) - [www.lernen-mit-Krebs-zu-leben.ch](http://www.lernen-mit-Krebs-zu-leben.ch)).

As clearly stipulated in the association's goals, the program and materials are regularly evaluated. Booklets, for example, are reviewed and modified before presenting them to patients for input. Collaboration with a young and inspired graphic artist has given a final artistic touch to the materials.

Contact over the years with a group of motivated professionals encouraged Gertrud Grahn to establish a contract with our association in 2004 which gave us the copyright to the program. This important development means that providing the Living with Cancer program with the respect that it deserves as intended by Gertrud, lies in our hands.

Starting a new group is never an easy task. In the past, course leaders have experienced negative reactions from their colleagues and the medical staff who were not only fearful that patients and families would learn "too much" about cancer, but also that nurses were providing them with this important information. As underlined by Gertrud Grahn, "using the Learning to Live with Cancer model is an entrance into an incredibly stimulating area in cancer care". This is exactly what is being experienced by a group of oncology nurses in Switzerland and in many European countries as well.

# TARGET

TARGET is an exciting new educational initiative from EONS. The goal of this project is to enhance European oncology nurses' understanding of the role and relevance of the Epidermal Growth Factor Receptor (EGFR) in cancer care. The official launch of the initiative will be at a special VIP event to take place during ECCO-13 in Paris.

As with all EONS educational initiatives, TARGET is based on the learning needs of European oncology nurses. A learning needs assessment, undertaken between March and April of 2005 in six European countries, provided valuable information on knowledge deficits related to EGFR. The results from this survey will be presented on Wednesday November 2nd at ECCO-13.

The TARGET project team drew on the results from the assessment to develop the TARGET course format and informational materials. The TARGET course consists of 6.5 student contact hours and includes sessions on:

- The molecular biology of cancer;
- The pharmacology of EGFR and its targeted use in cancer;
- Nursing considerations for patients receiving EGFR inhibitors;
- Providing support for patients with advanced cancer
- Writing and implementing a plan for dissemination of knowledge gained through attendance at the TARGET course.

Before attending a TARGET course, participants will be asked to undertake some pre-course work with the aim of revising and updating their basic knowledge about cell biology. As a means of educating as many nurses as possible on EGFR, participants will be asked to complete a dissemination project in the 6-month period following the TARGET course.

## Keeping European Oncology Nurses Up-to-date on Treatment Advances

The TARGET course format and draft materials will be piloted in a number of courses to be held later on this year. The first pilot course will take place on November 17th in the UK and this will be closely followed by the German pilot course on December 2-3rd. The Belgian pilot is scheduled for early January 2006. Further details about these pilots are available from the national oncology nursing societies in the various pilot countries.

TARGET materials will be revised in light of feedback from the pilot courses and the final version of the materials will be used during the TARGET Train the Trainer course that will be held in May 2006. The purpose of the Train the Trainer course is to prepare TARGET trainers to run courses in their own countries. Attendance at the Train the Trainer course is limited and will be awarded on a competitive basis. Applications for participation are welcome from experienced cancer nurses from across Europe who are willing to make a commitment to run TARGET courses in their own countries. Further details and an application form will be available at ECCO-13 and posted on the EONS website in November 2005.

European implementation of the course will take place from June 2006 onwards. If you are interested in learning more about the TARGET project please contact EONS President Jan Foubert at [jan.foubert@skynet.be](mailto:jan.foubert@skynet.be)

*TARGET is supported by an unrestricted grant from Merck KGaA, Darmstadt, Germany*

## Speak Up! Survey of European Oncology Nurses Shows CINV is a Major Concern

Jan Foubert, President EONS

### Oncology nurses want more information about newer treatment therapies

Concern, compassion and the desire to improve patient care were clearly conveyed in the results of a survey fielded recently among oncology nurses in Europe. Nurses in the UK, Italy, Portugal, Spain, and the Netherlands participated in the survey, which is an element of the EONS "Speak Up!" programme to encourage patients to speak up about their chemotherapy-induced nausea and vomiting (CINV) symptoms and to help nurses advise and educate patients on identifying and managing CINV. The survey was developed to assess attitudes of oncology nurses in Europe toward the effects of chemotherapy on their patients' quality of life and to understand how patients and nurses communicate. The results indicated that CINV is a major concern for both nurses and patients.

According to the survey, oncology nurses view nausea and vomiting as the primary concern among patients undergoing chemotherapy, followed by fatigue and hair loss. Over 70% of the respondents always talk with their patients about CINV at the start of every chemotherapy cycle; a further 26.4% discuss CINV with their patients frequently. This discussion is most often initiated by the nurse, not the patient, according to the survey (85.3% nurse, 14.7% patient) underscoring



the need for nurses to have the most up-to-date information available. These results reinforce the need for the "Speak Up!" programme designed to improve nurse-patient communication.

The need for effective treatments for CINV was obvious to the nurses surveyed.

79.8% believe CINV severely affects patients' quality of life, and 56.6% stated CINV sometimes affects patient's compliance with their therapy. However, only 31.4% of the nurses were aware of new anti-emetic treatments. When asked whether they would use new therapies if available, a vast majority (88.5%) said yes.

Some effective therapies to manage CINV, which can improve overall treatment outcomes and improve patients' quality of life while undergoing chemotherapy treatment include:

- Benzodiazepines – used to treat the anxiety that may lead to anticipatory CINV
- 5-HT<sub>3</sub> receptor antagonists – given IV or orally, useful to combating acute CINV
- Substance P receptor antagonists – a new class of treatments that work by blocking nausea and vomiting signals transmitted by the neurotransmitter, Substance P, in the brain (given in conjunction with the steroid dexamethasone)

The organisations participating in the survey included the UK Royal College of Nursing, the Sociedad Espanola de Enfermeria Oncologica (SEEO), Associazione Infermieri de Assistenza Oncologica (AIAO), Nederlandse Vereniging van Oncologie Verpleegkundigen (VVOV), the UK Cancer Nursing Society, and Escola Superior de Enfermagem Cidade de Porto. Responses were fairly even among the various organisations with a few interesting statistics. The highest percentage of nurses who “always” speak with their patients about CINV (91.5%) came from the Netherlands; which also had very high percentage of respondents (91.5%) who believe that CINV severely affects the quality of life for their cancer patients. Nurses in the UK Cancer Nursing Society and the VVOV indicated the highest number of nurse-initiated conversations regarding CINV. The most patient-initiated conversations occur in Italy and Spain, where high numbers of respondents also indicated that CINV affects both patients’ quality of life and their compliance with chemotherapy treatment. Spanish and Portuguese nurses

would most readily consider using new therapies for CINV.

The nurses participating in the survey made it clear that they are deeply involved in their patients’ care, taking the initiative to discuss CINV frequently with their patients. They are highly motivated to learn about and use new treatments to alleviate CINV, which they all agree continues to be a problem in cancer patient care. The “Speak-Up!” programme will promote and encourage effective two-way communications, enabling patient and nurse to work together to improve the patient’s quality of life and make nurses aware of all the available treatment options to alleviate CINV. The depth of the patient care being provided by oncology nurses was clearly demonstrated in this survey.

*An unrestricted educational grant was provided by Merck MSD. to support the implementation of this project.*

# From Curriculum to Accreditation: Assessing Educational Quality

Sara Faithfull  
Chair, Education Group and Accreditation Council

EONS accreditation is not only a means to endorse a product but it is also a process used by cancer nurses to evaluate quality and educational relevance of courses thereby providing professional credibility. Over the past 5 years, over 22 long and short courses have been accredited by the EONS Accreditation Council. Recently, the Educational Group undertook a review of EONS accredited courses. The purposes of this review were to gain an estimate of how many nurses were receiving professional development using EONS accredited programmes and to explore how competencies and educational credits were being utilised within Europe.

There have been many changes in the treatment of cancer that are now reflected in multi modality therapy and new ways of managing cancer in different care settings. These changes in treatment and treatment delivery have made it necessary to take a new look at the EONS Post-Basic Curriculum. As a result, changes have been made to the revised framework to reflect not only new thinking in oncology but also to reflect changes in educational methods. The developments within education have been quite dramatic in the last 5 years with the advent of the Bologna Declaration of 1999 and the subsequent changes in academic and vocational educational structures within Europe. As stated in the Bologna Declaration (1), educational institutions across Europe are expected to comply with the specified revisions by the year 2010.

The Bologna Declaration includes nine action lines for education:

- Adoption of a system of easily readable and comparable degrees
- Adoption of a two cycle education system (Degree, Masters)
- Establishment of a credit system
- Promotion of mobility
- Promotion of European cooperation in quality assurance
- Promotion of the European dimension of higher education
- Lifelong learning
- Higher education institutions and students
- Promoting the attractiveness of the European higher education system

The impact of these changes on vocational courses is that learning outcomes and competencies for practice need to be more clearly defined and that credits will be awarded based on length of study and learning outcome. These credits are transferable across countries providing increased mobility and transferability of qualifications. Although there is still much work to be done in developing educational structures, these changes need to be reflected in future nursing curriculum and professional development.

## Methods

A questionnaire was sent to course leaders of accredited programmes offered in 2004 and 2005. Of the 15 questionnaires that were sent, 11 were returned (73%). The questionnaire asked about course cohorts and numbers,

rates of successful completion, deferrals, and credits awarded. Further, answers to questions on whether external review and student evaluation was undertaken and if any changes had been made to the current programme were solicited by the questionnaire.

## Results

Although information provided on many of the returned questionnaires was incomplete, the course leaders gave an interesting picture of the cancer courses and developments ongoing within nursing (Table 1). Over 500 nurses undertook EONS accredited professional development in 2004/5. Of these, 305 participated in courses based on the EONS post-basic cancer nursing curriculum and 234 on specialised subject education.

**Table 1: Characteristics of Educational Courses, Number (%)**

Course characteristics	Responses (N=11)
Local educational credits used	2 (18%)
ECT credits used	1 (9%)
External examiners	11 (100%)
Evaluation and feedback provided by participants	11 (100%)
Clinical performance or competence assessed	1 (9%)

Few of the courses had attached academic credits (18%) which meant that the education was not necessarily transferable within institutions or countries and was not able to be used to build upon existing professional qualifications as proposed in life-long learning. Commendable was that all courses used appropriate quality assurance techniques and had positive feedback from external examiners and reviewers. Few of the courses utilised competencies in practice and only one programme evaluated clinical performance as part of their educational provision. Although practice was central to cancer nursing education, this was assessed through case studies and knowledge of topics rather than the actions of the nurse in practice. Changes within courses included: an increase in focus on care of older people, more specialist education topics, and more content on palliative care within cancer nursing courses.

Future cancer nursing courses will need to adapt to meet the changing educational structures within Europe. The impact of these changes will not only facilitate greater transferability of education across Europe but will also require academic recognition for practice elements and the assessment of competence. These changes will provide benefits for cancer nursing but will require an increasing vision of education as practice.

## References:

1. *From Berlin to Bergen: General report of the Bologna follow-up group* (<http://www.bologna-bergen2005.no/> accessed 27/7/2005)

# Presidential Insight: An interview with Jan Foubert

*It is difficult to imagine that the name Jan Foubert would not be recognized by a member of EONS. Jan served on the EONS Executive Board in the capacity of Board Member for four years, as President-elect for two years, and as President of the Society for the past two years. Throughout these 8 years, Jan performed the duties of Treasurer for the Society in addition to other responsibilities. In October, Jan will hand-over the leadership of EONS to Yvonne Wengström. In the following interview, Jan provides us with some parting thoughts on future issues facing EONS, accomplishments of the Society to date, and his personal reflections on his term as President of the Society.*

*In your opinion, what has been the single most significant event to impact on EONS development during the 8 years that you served on the EONS Executive Board?*

In my opinion, EONS has developed substantially in the last 8 years. Most recently, EONS has been very productive and innovative in the design of educational projects.

Based on a learning needs analysis, designed by experts in the field, pilot tested, and implemented with the support of national oncology societies, these projects really do impact the workforce of oncology nurses. Similarly, communication with members has changed substantially. The EONS Newsletter and the EONS website have become valuable information tools. A member who claims not to know what EONS is doing or what EONS stands for, is, in my opinion, someone who lives on another planet.

*You were instrumental in the design and implementation of the EONS Strategic Plan. How would you rate the success of the plan in achieving outlined goals to date?*

I think that the mission of EONS has become “a mission with a meaning within a European context”. The CARE strategy focuses on the 4 pillars that are the reason for the existence of EONS. The success of this strategy is linked to the fact that the strategy was developed with input from the Executive Board and the Advisory Council. The Advisory Council has understood that they are responsible for the design of the future of oncology nursing.

In the future, the role and responsibilities of the EONS Board will be much clearer. This is a result of identifying and clearly specifying tasks and responsibilities of Board Members and I really hope that the new Board will find this new organizational structure helpful.

In the area of research, I think EONS should become more pro-active in the future. The influence of the political agenda will always be the most difficult part of the Strategic Plan to implement since politics is not always very well known to nurses at local or European levels.

*What professional and personal lessons have you learned during your term as President?*

At a professional level, I had received almost no support from my institution. Although my employer found it good that I was President of EONS, they still expected me to carry out my job-related responsibilities as previously done and on time in a correct manner. In Belgium, my presidency was not recognised at all; my contacts with the two national societies remained as before my presidency. In a positive light, I was able to establish a network with academicians in other settings and this will continue to be advantageous for my professional life.

At a personal level, you can't be President of EONS 24 hours a day for 761 days without the support and understanding of your partner. I had discussed what effect the EONS presidency would have on my private life with my partner before starting the job (knowing what the job would entail based on my past experiences as an EONS Board Member) and I can only say that the experience had a positive impact on my relationship.

As President, you meet a lot of people; some become your enemy, most become your friend, and some try to protect you if others try to make your life miserable. I learned that it is sometimes difficult to be honest. A lot of people don't like to be told what you really are thinking. On the other hand,

it is really counter-productive and a waste of time if you don't speak openly with people. I had the opportunity to visit a lot of countries during my presidency, most often in relation to managing ongoing projects. I visited The Netherlands, the UK, Ireland, France, Sweden, Portugal, Spain, Switzerland, Germany, Poland, Serbia and Montenegro, Portugal, Canada, the US, Australia, Hungary, Italy, Turkey and Denmark. In all those countries I had the opportunity to meet with cancer nurses which was a real incentive for me to continue the work I was doing.



*The organizational structure of FECS may change in the near future. At the last Advisory Council meeting, the possibility of EONS splitting from FECS and becoming an independent organization was discussed. In this light, what are the strengths of EONS that would allow the Society to exist and prosper as an independent nursing organization in Europe?*

As I noted at the Advisory Council meeting, EONS is right now in a position to be “independent” although this means that we have to work on a structure that allows us to stay independent in the future. Being independent means having the resources to lead and to govern the Society. I think we should not completely close the door to opportunities which allow us to be associated with other societies. FECS has to define what it means by multidisciplinary and EONS has to continue to strive to obtain a real place for oncology nursing within the FECS organizational structure.

*Governmental policies on the role of pharmaceutical companies in providing financial support to health care professionals and professional organizations may impact on the ability of EONS to provide educational programs in the future. From your experience, do you see this as a reason for concern?*

This is a real concern. EONS is a registered UK charity and I have seen a lot of changes during my 8 years in EONS. We have to be honest; the pharmaceutical industry has the resources to help us implement our ideas. EONS has established a clear policy regarding education and this is very helpful for the industry as well as for EONS. At this time, we have not encountered any problems and the support we receive was never as good as it is at present. But, I agree, the future may be unclear.

*If you were to choose one area or topic on which EONS should concentrate future efforts, what would that be?*

I think we should be more pro-active. For example, educational projects should focus on future trends. Distance learning and other models of education should be considered. EONS should attain quality cancer care through education, research, leadership and advocacy and advance excellence in oncology nursing through professional and organisational vitality. Certain topics such as palliative care and clinical leadership deserve more attention in the future.

*Successfully juggling job, personal life and EONS responsibilities takes a special person with special talents. What is the secret of your success?*

Discipline – I am a very disciplined person. I completed my studies while working. To do this, you must be organized and disciplined. I work every day for EONS, 7 days a week. Doing a little work each day helps to avoid work piling up to the point where you don't see a light at the end of the tunnel. Another secret is to do things that you are able to do and to learn first about things you are uncertain of before trying to tackle these tasks. Finally, you have to like and enjoy the tasks that you are expected to perform. I enjoyed every minute of my presidency and this is the most important secret to survival.

# A Goodbye from Boardmembers

## Cath Miller, UK

It is hard to believe that after 6 years I will relinquish my place as an EONS Board Member, at the end of the ECCO13 in Paris. When I was asked to reflect upon my term of office, I eagerly said yes, then immediately started to consider how I could possibly break down or begin to do justice in writing, my experiences. However, here are some.....!

Firstly, I would like to pay tribute to the past and present Presidents of EONS. I have had the privilege of serving four Presidents over the 6 years, all of whom have used their unique and diverse leadership styles to take forward and represent EONS through times of great change in health care in Europe. They have embraced this change and challenged political and professional arenas in Europe, to promote a greater awareness and understanding of the unique contribution of cancer nursing.

My thanks to them all, who have given up so much of their personal time to represent and direct us. True innovators one and all!

A great sadness will be missing all my other Board colleagues who have become friends. The shared experiences, laughter, sadness sometimes arguments will stay with me through life, but most of all is the respect I have for each and every one in their professional lives who exemplify the professionalism of nursing. Their diverse backgrounds encompassing education, research management and clinical make a creative 'melting pot' of ideas and experiences that direct the future of EONS. To the new board members who will take up position this year, a heartfelt welcome and enjoy your experience. During the past 6 years, I have learnt so much from other individuals, cultures, systems and processes that I have been able to use in my own working life. For that I am grateful, and it has opened my eyes to the significant work that is yet to be undertaken on behalf of cancer patients and their families.

To my colleagues who form the Advisory Board and represent so many countries and nurses, remember you are EONS future. We exist to support you through your stages of development, help you network and harness the enormous potential that is European Cancer Nursing. It is heartening to see emerging from adversity a growing voice who want to see change through better education, research and practice. These innovators and innovations lie in each and every member, and is such a powerful voice. I wish you all well in the challenges you face in your own countries and use that potential to bring to the European stage so all can share these experiences in a transparent way.

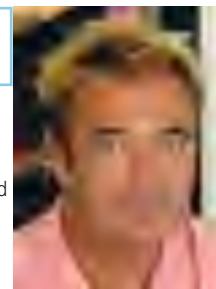
Lastly, a personal frustration of mine! I remain (at present) the only Board Member who does not speak a second language. I have tried (and failed) to learn Spanish although I could probably order drinks if asked!!! I have continued to be humbled by my colleagues who can slip in and out of other languages with ease. However, I think my experience on the Board has improved my own non verbal skills, and happiness, laughter, sadness, empathy can be shared irrespective of language barriers and how powerful they are!

I hope to meet many of you at ECCO 13 in Paris. Please do say hello if you see me and if not I wish one and all, peace, happiness and health.

## Giel Vaessen, EONS Past-president, The Netherlands

### Commitment and Fulfilment of a Promise

After serving 8 years as Board Member, it is time to leave this privileged position in EONS. I say goodbye with mixed feelings. On one hand it is a relief to hand over the responsibilities of guiding and directing EONS to the new team. On the other hand, it is difficult to leave the Board at this most crucial decision-making moment for the future of EONS.



During the last years, a tremendous improvement has taken place as EONS developed into adulthood as a professional society. The new strategy has been initiated together with the national societies, the business plan is finished, and the future in terms of close cooperation and relationship with the national societies looks promising. It is thanks to the work of the Board and the members of the Advisory Council that we can say: "we are EONS".

I still believe in collaboration with all our colleagues in oncology. As a nursing society, we are in the position to become a more serious partner in the field of decision making and influencing the best care for our patients all over Europe. For this reason we need to identify real leaders in oncology nursing on a European as well as on a national level who have the skills and persuasiveness to encourage oncology nurses to believe in their tremendous power as a full member of the multi professional team. Nursing is a recognized profession but it does not exist in isolation. The need to build up a close and strong partnership with other healthcare professionals is of uttermost importance in the future.

Decisions about EONS's future need to be well thought-out and can only be made in consultation with our members. EONS's current position and strengths are the result of hard work, enthusiasm, perseverance and the establishment of working relations with our partners in the field of oncology. These most important achievements need to be retained.

I say goodbye and want to thank all my colleagues and special friends that I have met during my term as EONS Board Member. *Thank you for your commitment and enthusiasm and thank you especially for your belief and faith in the future of oncology nurses in Europe.*

## Karin Ahlberg, Sweden

To have EONS as a 'playground' makes an impact on one's life in numerous ways. Firstly, it provides an opportunity to collaborate with colleagues. Secondly, it gives a new perspective on what cancer nursing is all about. Thirdly, it brings pleasure in knowing that one has friends all over Europe.

I have had four exiting years serving as an EONS Board Member. When I leave the position, I will have gained a lot of nice memories. I have also an insight in how much more there is to do if we want to further develop and improve cancer nursing in Europe. One of the most important tasks in the future may be to work for an increased amount of highly educated oncology nurses, e.g. on a PhD level, that are still involved in the clinical care of the cancer patient. Another task will be to improve the standard of care through an increased implementation of evidence-based nursing interventions.



I really wish the new Board Members the best of luck with their new roles and the EONS work ahead of them. *I know that your work can and will make a difference for the further development of cancer nursing in Europe.*

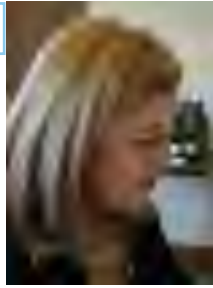
## Paz Fernández, Spain

It is not easy to concentrate in a few words all the experiences I have accumulated in my six years at the EONS Board.

Contacting new people. I have met clinical nurses and administrative leaders from all over Europe. We have shared our professional concerns and we have shared many good personal moments at EONS events. I can assure you that these experiences will be in my mind and in my life for a long time in the future. I have learnt so much from each one of you. Throughout these years, I have realized that we have more in common than differences, although obviously diversities exist in each country.

The experience on the Board. Although my term on the Board was difficult at first, there were so many EONS projects that I wanted to learn more about and I had so many questions that I wanted to ask, I survived after a few sleepless nights and some moments of re-thinking my decision to join the Board.

The most important happening within EONS during the last years has been the increasing recognition that nurses are the key persons in the team to provide information on cancer care to patients and families. I strongly believe that this is the first step to turn many more ideas into reality.



Nurses have been aware of the patient-centred needs as the main direction we take in our work as opposed to the disease-orientated biomedical model we used some years ago. This model for our practice has steadily changed in the course of my 24 years of professional life and I am happy to hear about how nurses' concerns are now becoming more focussed on older people and special groups.

In my opinion, we have succeeded in increasing the influence of cancer nursing in the political agenda in Europe and this influential role has been one of the major EONS goals for starting the new century. It has been a struggle to obtain these results, but our voice is stronger today and I am glad that we have finally gotten the first chance to be heard in the European arena.

For the future, I can tell you that this is an exciting time to be involved in EONS. Many years and many efforts from our colleagues have allowed us to grow and to incorporate new European countries into our nursing society. Many changes have taken place in cancer nursing education, new technologies, new treatments and new targeted therapies. These events require nurses to take a leadership role in addressing patient's needs. The challenge for the new era is to develop an optimistic view about cancer nursing and to find value in our work as cancer nurses in order to improve our practice more and more each day.

Following my personal logo: "Growing old is mandatory, growing wise is optional", I say good-bye to you. I will be with you forever and you will be with me...

## A Summary of ECCO 13 Nursing Abstracts of Interest

*Educational offerings at the ECCO conference, Europe's largest multi-disciplinary cancer conference, are so extensive that it is difficult for most participants to attend every session that could be of benefit to them. Therefore, a number of abstracts were selected and summarized. These abstracts were chosen to be of special interest as they either present information on fundamentals of cancer nursing, new trends in nursing practice, results of state of the art nursing research, or nursing management issues.*

*Note: only the presenting author and their affiliated institution are provided. Please consult the ECCO Abstract Book or CD-ROM for a complete list of all authors.*

### **Post-cancer fatigue: has your patient visited the osteopath?**

*P. Rodrigus, Catharina Ziekenhuis, Radiotherapie, Eindhoven, The Netherlands*

Post-cancer fatigue is recognized as a problem that negatively impacts on daily activities. The purposes of this interventional study were to evaluate if osteopathic therapy has an effect on mobility and dysfunctions identified at baseline assessment, and to assess if treatment of liver dysfunction has an effect in the total management of cancer fatigue.

13 patients received 3 osteopathic treatments. Treatment evaluation was performed using the FACT (quality of life assessment tool) questionnaire pre- and post-treatment.

Patients with post-cancer fatigue had signs of liver congestion and loss of liver mobility at initial diagnosis. Osteopathic treatment of liver dysfunctions resulted in significant improvement in fatigue. Normalisation of other dysfunctions in the parietal, visceral or craniosacral system had a significant positive effect on fatigue complaints. Osteopathy is useful in the treatment of post-cancer fatigue.

### **Train the trainer method for a prospective oral mucositis audit (POMA): A report from the collaborative EBMT nurse/physician mucositis advisory group**

*B. Quinn, Royal Marsden NHS Trust, School of Cancer Nursing &*

### **Rehabilitation, London, UK**

Oral mucositis (OM) is a frequent and debilitating consequence of cancer treatment. The true incidence and duration of OM are largely unknown due to inaccurate assessment and under-reporting. Proper training of health care professionals can lead to substantial improvement in consistency and accuracy of OM assessment which is necessary to conduct clinical trials to evaluate new therapies to manage OM. Twenty-two nurses and physicians were trained on OM assessment and scoring using the WHO oral-toxicity scale: these persons then trained nurses on OM assessment who then themselves performed OM assessment.

Nine sites were trained.

The train the trainer method demonstrated that joint physician nurse training can aid clinical research in OM and improve patient care.

### **Decision-making at the end of life in critically ill cancer patients**

*N Pattison, Royal Marsden NHS Trust, Critical Care, London, UK*

Decision-making at the end of life is difficult for patients, family members, and nursing staff with exacerbation of the situation if the patient is critically ill. Appropriate decision-making at this time is important to ensure a timely transition of care. Nurses, as patient advocates, are in a prime position to ensure that the decision-making is an inclusive process, patient needs are paramount, the practical aspects of withdrawal lead to a smooth transition and that comfort measures are implemented. In this presentation, the following phenomena will be discussed in relation to cancer patients using case studies: over-treatment, decision-making and conflict, and covenants of care. The enactment of good decision-making at end of life in critically ill cancer patients and resolution of conflicts in care paradigms will be proposed.

### **Older people's perceptions about information, decision-making and treatment following a diagnosis of cancer**

*N. Kearney, Cancer Care Research Centre, Department of Nursing and Midwifery, University of Stirling, UK*

Studies have identified inadequacies in the care and treatment received by older patients with respect to diagnosis, ineffective symptom management

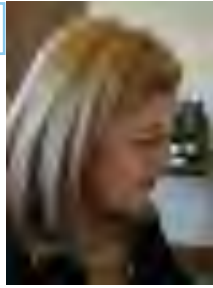
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The most important happening within EONS during the last years has been the increasing recognition that nurses are the key persons in the team to provide information on cancer care to patients and families. I strongly believe that this is the first step to turn many more ideas into reality.



Nurses have been aware of the patient-centred needs as the main direction we take in our work as opposed to the disease-orientated biomedical model we used some years ago. This model for our practice has steadily changed in the course of my 24 years of professional life and I am happy to hear about how nurses' concerns are now becoming more focussed on older people and special groups.

In my opinion, we have succeeded in increasing the influence of cancer nursing in the political agenda in Europe and this influential role has been one of the major EONS goals for starting the new century. It has been a struggle to obtain these results, but our voice is stronger today and I am glad that we have finally gotten the first chance to be heard in the European arena.

For the future, I can tell you that this is an exciting time to be involved in EONS. Many years and many efforts from our colleagues have allowed us to grow and to incorporate new European countries into our nursing society. Many changes have taken place in cancer nursing education, new technologies, new treatments and new targeted therapies. These events require nurses to take a leadership role in addressing patient's needs. The challenge for the new era is to develop an optimistic view about cancer nursing and to find value in our work as cancer nurses in order to improve our practice more and more each day.

Following my personal logo: "Growing old is mandatory, growing wise is optional", I say good-bye to you. I will be with you forever and you will be with me...

## A Summary of ECCO 13 Nursing Abstracts of Interest

*Educational offerings at the ECCO conference, Europe's largest multi-disciplinary cancer conference, are so extensive that it is difficult for most participants to attend every session that could be of benefit to them. Therefore, a number of abstracts were selected and summarized. These abstracts were chosen to be of special interest as they either present information on fundamentals of cancer nursing, new trends in nursing practice, results of state of the art nursing research, or nursing management issues.*

*Note: only the presenting author and their affiliated institution are provided. Please consult the ECCO Abstract Book or CD-ROM for a complete list of all authors.*

### **Post-cancer fatigue: has your patient visited the osteopath?**

*P. Rodrigus, Catharina Ziekenhuis, Radiotherapie, Eindhoven, The Netherlands*

Post-cancer fatigue is recognized as a problem that negatively impacts on daily activities. The purposes of this interventional study were to evaluate if osteopathic therapy has an effect on mobility and dysfunctions identified at baseline assessment, and to assess if treatment of liver dysfunction has an effect in the total management of cancer fatigue.

13 patients received 3 osteopathic treatments. Treatment evaluation was performed using the FACT (quality of life assessment tool) questionnaire pre- and post-treatment.

Patients with post-cancer fatigue had signs of liver congestion and loss of liver mobility at initial diagnosis. Osteopathic treatment of liver dysfunctions resulted in significant improvement in fatigue. Normalisation of other dysfunctions in the parietal, visceral or craniosacral system had a significant positive effect on fatigue complaints. Osteopathy is useful in the treatment of post-cancer fatigue.

### **Train the trainer method for a prospective oral mucositis audit (POMA): A report from the collaborative EBMT nurse/physician mucositis advisory group**

*B. Quinn, Royal Marsden NHS Trust, School of Cancer Nursing &*

### **Rehabilitation, London, UK**

Oral mucositis (OM) is a frequent and debilitating consequence of cancer treatment. The true incidence and duration of OM are largely unknown due to inaccurate assessment and under-reporting. Proper training of health care professionals can lead to substantial improvement in consistency and accuracy of OM assessment which is necessary to conduct clinical trials to evaluate new therapies to manage OM. Twenty-two nurses and physicians were trained on OM assessment and scoring using the WHO oral-toxicity scale: these persons then trained nurses on OM assessment who then themselves performed OM assessment.

Nine sites were trained.

The train the trainer method demonstrated that joint physician nurse training can aid clinical research in OM and improve patient care.

### **Decision-making at the end of life in critically ill cancer patients**

*N Pattison, Royal Marsden NHS Trust, Critical Care, London, UK*

Decision-making at the end of life is difficult for patients, family members, and nursing staff with exacerbation of the situation if the patient is critically ill. Appropriate decision-making at this time is important to ensure a timely transition of care. Nurses, as patient advocates, are in a prime position to ensure that the decision-making is an inclusive process, patient needs are paramount, the practical aspects of withdrawal lead to a smooth transition and that comfort measures are implemented. In this presentation, the following phenomena will be discussed in relation to cancer patients using case studies: over-treatment, decision-making and conflict, and covenants of care. The enactment of good decision-making at end of life in critically ill cancer patients and resolution of conflicts in care paradigms will be proposed.

### **Older people's perceptions about information, decision-making and treatment following a diagnosis of cancer**

*N. Kearney, Cancer Care Research Centre, Department of Nursing and Midwifery, University of Stirling, UK*

Studies have identified inadequacies in the care and treatment received by older patients with respect to diagnosis, ineffective symptom management

and lower survival rates. This study aimed to identify and describe the experiences of older people with cancer and to develop a clinically meaningful framework for practice.

A total of 41 patients were recruited: 24 from a specialist cancer centre and 17 from an elderly care unit. Single, semi-structured interviews were conducted. Cognitive and physical status was assessed at time of interview using standardised measures. Data were analyzed using framework analysis. Key themes in relation to older people's experiences of cancer included: trust in health professionals, information and understanding, treatment expectations, experience of side effects, hopefulness and despair. On the basis of these themes, a framework consisting of strategies for clinical practice and decision-making has been developed.

#### **Peripherally inserted central catheters and implanted ports. A retrospective analysis of the complication rates and evaluation of associated costs**

*V. McInerney, University College Hospital, Haematology/Medical Oncology, Galway, Ireland*

Reliable central venous access is crucial for patients receiving chemotherapy. The aims of the study were to: examine and compare complication rates of peripherally inserted central catheters (PICC) and implanted ports and evaluate the associated costs.

Retrospective review of 114 cases in 2 hospitals with a total of 138 PICC or implanted ports was conducted.

There was a significant difference in the incidence of complications: 9.6 per 1000 days PICCs and 2.3 per 1000 days for ports ( $p=0.05$ ). Ports were superior to PICCs in terms of infection (11% vs. 31%;  $p=0.01$ ). Time from insertion to infection was 33 days for ports and 3 days for PICCs. The total cost of a PICC was 432 € compared to 2,711 € for a port.

Although the rate of complications was statistically more significant in PICCs, the type and site of these complications did not warrant substantial intervention compared with ports. This factor combined with lower costs justifies more extensive use of PICCs in selected patients.

#### **Exercise during cytostatic treatment: group cohesion and quality of life**

*J. Midtgaard, Copenhagen University Hospital, Centre for Nursing and Care Research, Copenhagen, Denmark*

Studies show that physical activity improves functional capacity and quality of life (QOL). Few studies have examined exercise carried out in a group setting. Group-based intervention combined physical activity with body awareness exercises, relation, and massage. Experiences with group cohesion and changes in social and emotional aspects of QOL outcomes were examined. Qualitative semi-structured group interviews were conducted post-intervention. Quantitative assessments ( $N=55$ ) of selected QOL dimensions were made at baseline and repeated after 6 weeks.

The group setting motivated individuals to pursue endeavours beyond their physical limitations. Significant improvements in relation to emotional functioning, social function, and mental health ( $p<0.05$ ) were reported. This study identified a conceptualization of group cohesion that forms a valuable basis for a randomized controlled trial to conclude whether the observed changes hide a causal link.

#### **The development of an interprofessional education course for those working in cancer care**

*A. Menon, King's College London University, London, UK*

Policy and professional literature support the notion that interprofessional collaboration is essential for quality patient care. A curriculum which reflected the cancer patient journey and incorporated care from a multiprofessional perspective was developed and delivered at a university ( $N=29$ ) and two Trust sites ( $N=36$ ): nurses and other health care workers attended.

Evaluation of the courses was positive and interviews indicated that participants felt better able to communicate with colleagues after course participation. Little effect on interprofessional working in the clinical area was evident.

Further research is needed to determine if short courses influence interprofessional working and subsequently patient care.

#### **Improving standards of nutritional care through the development of a nutritional care assistant role on a cancer ward: The first year's experience**

*M. Wells, University of Dundee, School of Nursing and Midwifery, Dundee, UK*

Although 40% of hospitalized patients suffer from malnutrition, the problem is largely unrecognised. This project aimed to improve nutritional care through the initiation of a Nutritional Care Assistant (NCA).

Baseline data on nutritional screening practices, patients' experiences of eating and drinking, staff knowledge and skills, and dietician referrals were collected. A comprehensive nutritional screening tool to identify patients at risk of malnutrition was introduced. Healthy snacks were routinely offered. Nutritional screening practices improved. Patient comments show that snacks were helpful.

Nutritional care was improved through the introduction of a NCA. Simple measures to improve food choice were well-evaluated by patients.

#### **A critical examination and discussion on the degree to which nursing practice is based on rigorously generated evidence**

*M. Morris, Auckland City Hospital, Auckland, New Zealand*

Interest in evidence-based healthcare and an increased focus on evaluating and improving clinical effectiveness is growing. So too is a call for nursing to become a research-based profession. Evidence-based practice could enable nurses to demonstrate their unique contribution to health care outcomes and support professionalization in terms of enhanced authority and autonomy.

This presentation focuses on how much, if any, of current practice is generated by evidence.

#### **Development of a clinical pathway in a palliative care unit**

*I. De Maesschalck, Palliative Care Unit, Antwerp, Belgium*

Coordination of the multidisciplinary team is important to assure high-quality patient-centred care in palliative care units. This can be achieved through a clinical pathway. The aim of the developed clinical pathway was to assure involvement of members of the multidisciplinary team, to provide maximum support to patients and families, to ensure optimal pain and symptom control and to optimise transfer between care settings. Records for admission, hospital stay and possible discharge or transfer were developed. Training sessions provided nurses with information on adapting pain treatment according to guidelines stated in the pathway. The pathway has been used for the past 1.5 years. It assures that the multidisciplinary team members are involved in care and increases nursing independence in relation to pain management.

#### **NGO initiatives for cancer rehabilitation: obstacles in resource poor settings [community initiative to bridge gaps]**

*D.S. Pramod, Health Alert Organisation of India (NGO), Cancer Care Cell, Dhule, India*

Cancer rehabilitation services are under-developed in resource-poor nations due to economical factors and a lack of expertise. Patients returning to villages after therapy need rehabilitation programs that suit their economic, social, and cultural background. The NGO is training youth volunteers and traditional faith healers in marginalized communities to provide rehabilitation support to cancer patients in rural areas.

To date 25 volunteers have screened 850 patients. Support programs are devised based on needs of patients and in consultation with family. The program, staffed by NGO volunteers, community leaders, local physicians and traditional faith healers, has developed into a well-organized program offering free rehabilitation services.

# First International Institute of Leadership



## in Cancer Nursing Held in Toronto

By Margaret Fitch,  
President International Society  
of Nurses in Cancer Care

The International Society of Nurses in Cancer Care has launched an exciting new learning opportunity for cancer nurses. The first International Institute of Leadership in Cancer Nursing was held in Toronto in June, 2005. The Institute was developed to bring cancer nurses together to learn about leadership and develop their skills in influencing change.

Making a difference and influencing change requires skills of leadership. So often the idea of leadership is associated with only formal positions in organizations. But leadership can come in many forms and can be enacted in many roles. Whether one is caring for an individual patient, teaching other nurses, introducing a new procedure, or working to have a patient's wishes followed by the cancer care team, skills of leadership are needed. Leadership is about making a difference in one's working environment. It is about feeling empowered to take an active role within one's sphere of influence.

Thirty cancer nurses from across Canada participated as attendees in the first International Institute on Leadership in Cancer Nursing in Toronto. They worked with five international faculty and five Canadian faculty, all nursing leaders in cancer care. Jan Foubert, President of EONS, was one of the international faculty members together with Sanchai Aranda (Australia), Petra Fordelman (South Africa), Cibele Andruccioli De Mattos Pimenta (Brazil), and Kevin Sowers (United States).

Participants wrote comments such as the following in their evaluations:

- *"This was the best conference and interactive workshop I ever attended. It promoted cancer nursing and leadership both."*
- *"A wonderful experience! The rigor and the networking activities were invaluable and stretched me personally and professionally."*
- *"This course stimulated an interest in learning more about ourselves and about how others see us. The tools I learned about will be very useful in the work that I do in my clinical setting."*
- *"I realized that I have strengths and weaknesses as a leader. I got positive feedback that I am able to contribute...leading comes from within, it is not a job description."*

The Institute was held over a two and a half day period. A series of plenary speakers, individual and small group learning experiences and pre-session

assessments by co-workers about leadership behaviors provided opportunities for the participants to learn. The majority of the time was spent in small group interaction where participants used clinical case studies to test and apply their thinking about leadership and involvement in workplace teams. The nurses had a variety of opportunities to identify ways to build on their personal leadership strengths and compensate for their leadership weaknesses. Each person has leadership roles that are preferred and others with which there is less comfort in performing. Part of being successful is to work with others who have strengths in those areas where as individuals we are not as comfortable or effective.

The International Society of Nurses in Cancer Care is planning for Leadership Institutes to be offered to cancer nurses on a region by region basis over the coming years. ISNCC hopes to collaborate with other cancer nursing societies or institutions to hold the Institute and build the capacity of cancer nurses to be effective leaders for change. By working on a regional basis the context of the discussions will be appropriate for the cancer care system and the role of cancer nurses in that part of the world.

The ISNCC is looking forward to collaborating with EONS to hold International Institutes on Leadership in Cancer Nursing in the near future. For information please contact [rachel@mediate-health.co.uk](mailto:rachel@mediate-health.co.uk)



## A new resource for oncology nurses!

Giel Vaessen, Netherlands & Hogeschool Zuyd, Bu Contracting Welzijn en Zorg, Heerlen, The Netherlands

How often do you care for patients receiving oral chemotherapy? Would you like more information to support you in this? For many of us, managing patients treated with intravenous therapy is traditionally more common than those receiving oral treatment. Oral chemotherapy regimens are associated with different issues and needs, which may be less familiar to the oncology nurse.

To help fill this gap, [www.Xeloda.Roche.com](http://www.Xeloda.Roche.com) has been developed to provide information and news about oral capecitabine (Xeloda®). Practical information about the management of patients with metastatic breast cancer, as well as early and metastatic colorectal cancer, specifically for oncology nurses, is presented in an extensive new section of the website. Designed to supplement existing sections on dosing and treatment, it includes:

Compliance: What causes non-compliance? How does recurrent disease affect compliance?

Side-effect management: Practical help in recognizing and dealing with the most common adverse events.

Providing support: Strategies to help you support your patients.

Literature, checklists and handouts for you and your patients are available in several European languages. Also, try the interactive case studies, specifically designed to inform, challenge, and extend your knowledge.

[www.Xeloda.Roche.com](http://www.Xeloda.Roche.com) is regularly updated with useful information and news. Registration is easy and quick – simply go to the website and submit your details. Once you receive your password you can start browsing.

# Management of Cancer-Related Symptoms:

## The importance of identifying barriers

Sofie Jakobsson

*Assessing and treating cancer-related symptoms, which are often not detected or alleviated, is a major task to improve cancer patients overall quality of life. Active symptom management has a role in every stage of cancer starting from the day of diagnosis. The consequences of inadequate symptom management are complex and can be looked at from many perspectives. Not only can untreated symptoms affect the patients' functional status and quality of life, but they also often negatively affect the psycho-social realm of the patient including personal, professional and social relations. Adverse symptoms may also impact on the next of kin in various ways. From a health care perspective, symptoms that are not well managed can impose a greater burden for the care givers.*

To date, research involving cancer-related symptoms is directed toward either a single symptom, such as fatigue or pain, or toward the response that can be associated with a symptom, such as anxiety. Most research aims to study the prevalence and experience of having specific cancer-related symptoms and to test new interventions. There are a few evidence-based interventions which aim to prevent or decrease cancer-related symptoms. But the fact remains that patients continue to report unrelieved symptoms. When conducting and implementing new interventions and new clinical guidelines, the issue of conceivable barriers in regards to a specific symptom management must be taken in consideration. In examining barriers to symptom management, most research refers to pain management which is associated with multiple barriers. But the few studies that have examined barriers to symptoms other than pain have shown that there are different sets of barriers associated with different symptoms. A research gap exists, however, in evaluating barriers for the management of most symptoms.

### **An unrecognized symptom is also an untreated symptom**

Issues related to inadequate assessment have been shown to be a common barrier from the patient's as well as from the caregiver's perspective. One of the most common recipient barriers is lack of awareness of need. Many patients may simply assume that symptoms are expected with a diagnosis of cancer. The frequently parallel belief that there is nothing to be done when a symptom occurs is a further barrier to receiving appropriate help. The fact that patients or their family caregivers may not see a specific symptom as a problem and that the patient may not want the recommended treatment makes treatment adherence almost impossible. This is an example of the many dimensions to the barriers related to assessment.

Reluctance to appear weak or foolish or unable to cope may all additionally contribute to a failure to report symptoms when they occur, even when the symptoms are troublesome. Patients may be reluctant to take the initiative and rather wait for a physician to introduce a topic. In other cases, patient's concerns about using limited clinic time to discuss what may seem to be unrelated or seemingly non-medical issues may cause patients to avoid these important topics in discussions with their caregivers. The experience of symptoms and their assessment can differ in relation to the patients' ethnicity and previous experiences. Various ways of expressing the symptom experience is of significance when assessing symptoms: assessment of individual beliefs and concerns is important to be able to explain and prevent barriers to the appropriate symptom management.

### **Attitudes, values and beliefs of nurses**

The attitudes, values and beliefs of nurses can also be barriers to assessing and alleviating symptoms. It has been reported that health



care providers may withhold treatment if they fear that treatment could hasten death. In relation to pain medications, nurses have a fear of causing addiction and of causing adverse side effects through their administration. Barriers to adequate symptom management can also include the belief that pain is inevitable in some stages of cancer. The assessment and treatment of cancer-related symptoms can be difficult due to the complexities and severities of symptom presentation which makes it difficult to treat a specific symptom. On the other hand, the treatment of a specific symptom may cause more distress than the symptom itself and therefore treatment is not given. Some studies have indicated that health care providers use various symptom management strategies for different age groups.

### **Knowledge, time and cooperation**

Time, knowledge and cooperation between nurses and physicians have been shown to be presumed barriers to symptom management. Nurses report a lack of time to assess symptoms and a lack of knowledge to be able to appropriately assess and treat symptoms. This indicates a need for more education to overcome this barrier. Patients also report that they need more information and knowledge concerning the treatment of their symptoms. Nurses as well as patients have reported that the unavailability of the doctor hinders symptom management. Other communication issues between nurses and physicians have been identified including the physician's reluctance to accept suggestions for symptom management made by nurses and accusations that nurses emotionally overreact to the situation.

### **Symptom clusters**

Clinical experience suggests that cancer patients experience multiple symptoms and it has been proposed that future research concerning cancer related symptoms should encompass symptom clusters. Symptom cluster is defined as three or more concurrent symptoms that are related to each other even if the symptoms do not share the same etiology. This phenomena calls for a new approach on assessing and treating cancer-related symptoms. The barriers identified for individual symptoms may not appropriately reflect barriers for symptom clusters. The discrepancy between how caregivers believe that symptoms interfere with each other and the interference that patients report presents difficulties and shows the importance of approaching cancer related symptoms in clusters.

### **Multidisciplinary perspective**

The studies that have examined barriers did not investigate symptom management from a multidisciplinary perspective. This is a major

## Clinical Summary

### Management of Cancer-Related Symptoms: The importance of identifying barriers

*Sofie Jakobsson, RN, Department of Oncology, Sahlgrenska University Hospital, Gothenburg, Sweden*

Assessing and treating cancer-related symptoms, which are often not detected or alleviated, is a major task to improve cancer patients overall quality of life. Despite the recognition of the importance of accurately assessing and managing symptoms, there are numerous barriers which prohibit members of the multidisciplinary team from providing patients adequate relief. One of the most common barriers is the patient's lack of awareness of the need to seek appropriate help. Educating patients and family members about expected and potentially serious symptoms and recognizing cultural beliefs that may affect the way a patient deals with a cancer symptom are important interventions to assure that the appropriate measures are taken. The attitudes, values and beliefs of nurses can also be barriers to assessing and alleviating symptoms. Further, a lack of time to assess symptoms and a lack of knowledge regarding the appropriate assessment and treatment of symptoms are barriers reported by nurses which interfere with symptom management. Despite improvements in collaboration between the various members of the health care team, poor communication between nurses and physicians has been identified as a barrier to managing symptoms.

Cancer-related symptoms do not often occur in isolation, but rather in clusters. Symptom cluster is defined as three or more concurrent symptoms that are related to each other even if the symptoms do not share the same etiology. This phenomena call for a new approach on assessing and treating cancer-related symptoms as the barriers identified for singular symptoms may not appropriately reflect barriers for symptom clusters. Further research is needed to investigate other barriers which interfere with the assessment and management of symptoms.

limitation of symptom management as the team of caregivers who are supposed to collaborate on revealing patient's cancer related symptoms consists of more professionals than just nurses and physicians. The roles of the different professions in the multidisciplinary team are often unclear and serve as an obstacle to implementing clinical guidelines.

#### Conclusions

To enhance knowledge on how best to establish clinical guidelines for symptom management from a multidisciplinary perspective, barriers and possibilities to effective symptom management must first be identified. Not only do we need to assess barriers to assessing different cancer related symptoms, but we also need to identify barriers from the perspectives of a multidisciplinary care team. Further, barriers to assessing symptom clusters need to be identified. In order to meet this gap in the knowledge of symptom management, studies need to be conducted which aim to describe these barriers as well as the possibilities to achieve effective symptom management from the perspective of nursing, medicine and other health care professionals. This evidence obtained from clinical studies must be examined before we are able to shape and implement clinical guidelines for assessment, treatment and evaluation of cancer-related symptoms. If we can achieve this, we will be able to enhance the daily life, the quality of life and the function of cancer patients

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## BONE:

*Jan Foubert, President EONS*

### educating nurses on bisphosphonates

A new educational initiative for cancer nurses is nearing completion, with BONE (Bisphosphonates Oncology Nurses' Education pack) currently going through final review. BONE has been developed with the support of Roche and will assist oncology nurses in determining the best course of advice and treatment for patients with metastatic bone disease. Research carried out by EONS in 2004 found that specialist education, and particularly information about the use of bisphosphonates in advanced, metastasised cancer, is inconsistent throughout Europe, and we hope that BONE will help address this.

BONE offers EONS the opportunity to use its international network to advance clinical nursing practice by raising awareness of metastatic bone disease and the issues surrounding patient management, while also providing information on recent advances in the availability of bisphosphonates to treat metastatic bone disease.

BONE is a self-learning course to fit in with busy lifestyles and work responsibilities, and contains modules on metastatic bone disease, the use of bisphosphonates and patient management issues. A short test at the end of each module will allow nurses to test their knowledge and identify opportunities for practical application.

Appreciation and thanks are due to Jan Foubert, President of EONS, and the senior oncology nurses who have reviewed and commented on BONE - Sarah Heatley, Sara Faithfull, Pauline McIlroy and Jackie Green. BONE will shortly be 'pilot tested' by a group of cancer nurses from London, and is expected to be formally launched in the Autumn of 2005. Nurses will then be able to apply for a copy of the pack via their national society.

# 5<sup>th</sup> EONS Spring Convention

Mark your calendars and plan to attend the 5th EONS Spring Convention to be held from April 20-22, 2006 in Innsbruck, Austria. The theme of the conference is Cancer in the Elderly: New developments, changes and implications for nursing. Due to the aging of the population in Europe, the incidence of cancer is predicted to rise to one third over the next two decades. This situation will challenge cancer nurses in many ways to deliver the best possible care.

With an emphasis on providing a state-of-the-art educative program which encourages interactive learning, the EONS Spring Convention has acquired an excellent reputation for high quality cancer nursing education. Topics to be covered at the 5th Spring Convention will include support systems, comorbid conditions and how to collaborate with medical colleagues to develop the best treatment plan. Top nursing speakers and gerontology experts including D. Boyle (USA), D. Porock (UK), JPF Slaets (NL), B. Thome (S), and L. Repetto (I) have agreed to share their wealth of knowledge. At a special EONS-SIOG Symposium, the noted medical oncologist, Dr. M. Apro, will present a lecture on supportive care in geriatric oncology.

The organising committee has succeeded in attaining a balance in the variety of instructional methods in place at the conference which will include plenary lectures by invited speakers and selected proffered papers on topics related to the care of the elderly cancer patient. Discussion forums and workshop activities will ensure that participants will enhance their knowledge from recognised experts as well as from experienced colleagues. Poster presentations and an industry exhibit round out the offerings at the Spring Convention.

In recognition of the multi-cultural backgrounds of EONS members, a selected number of workshop topics will be conducted in German.

The 5th EONS Spring Convention promises to be an excellent opportunity to browse, participate, contribute and share the art of cancer nursing practice—not to mention the opportunity to catch up on the latest EONS news! More information including the complete scientific program is available at the EONS website ([www.cancereurope.org](http://www.cancereurope.org)).

To help you better plan and prepare for your attendance at the convention, please take note of the following important dates:

**9 January 2006 – Deadline for abstract submission.** Topics for abstract submission include: Nursing skills in assessing older people with cancer; Impact of cancer in older people and their carers; Nursing interventions in the management of cancer in older people; Decision-making and communication; Clinical leadership and managing resources for older people with cancer; and Applied research in cancer care in the older person. On-line abstract submission is available at [www.fecs.be](http://www.fecs.be).

**9 January 2006 – Deadline for applications for fellowship grants.** Grants including free conference registration, free accommodation and 500 EUR for travel expenses will be awarded to nurses from countries with limited resources to support their attendance. Applicants should supply a short CV as well as a brief letter explaining the benefit for them to attend the convention. Applicants must be fluent in English or German. Further information is included in the program announcement or from the EONS Secretariat.

**1 April 2006 – Pre-registration deadline.** Early registration rates are considerably reduced. EONS members are eligible for further reduced rates. On-site registration only is available after 1 April. On-line registration is available at [www.fecs.be](http://www.fecs.be).

## Novice Cancer Nursing Research Workshop

Due to the positive response from the first research workshop, the second pre-Spring Convention introductory research workshop will be held on Wednesday, 19 April, 2006. Topics to be presented include an introduction to nursing research, the identification of researchable questions, ethical issues in researching vulnerable individuals, the research-related challenges to practice. Pre-registration is required and participation will be restricted to the workshop. A maximum of 40 participants will be permitted in the English-language workshop and 20 in the German-language workshop. The registration fee is €25.

## Call for applications for the Novice Researcher Award 2006

As part of the Society's ongoing strategy to promote the conduct, dissemination and utilisation of oncology nursing research, the European Oncology Nursing Society is pleased to announce the Novice Researcher Lecture at the 5th EONS Spring Convention which will take place in Innsbruck, Austria, 20-22 April 2006.

EONS invites the members to apply for this prestigious award. The successful candidate will be invited to attend the Spring Convention and to deliver the Award Lecture.

Conference fees and hotel as well as travel expenses will be covered.

Applications are welcome from novice nurse researchers who are currently actively involved in nursing research and who are willing to present the successful project during the Spring Convention.

Applicants should submit a summary in English of their work in no more than 1500 words along with an abstract (a summary of the work on one A4 page), which will be published in the proceedings book of the Spring Convention and a short curriculum vitae with a passport size photo.

Applicants must be members of the European Oncology Nursing Society. A group of nurse researchers of the board of EONS will review the applications. Selection criteria will involve scientific merit, relevancy to cancer care, feasibility and expertise. Results will be communicated in January 2006.

Applications should be submitted to the EONS office no later than **November 16<sup>th</sup> 2005**.

We are looking forward to receiving applications from many nursing colleagues all over Europe.

Good luck and best wishes,



Jan Foubert  
President EONS