



## Train the Trainer programme

The ISNCC has held five Train the Trainer breast cancer programmes since the first one held in 2000. The most recent, held at the 16<sup>th</sup> ICCN in Atlanta, sponsored by a grant from Sanofi Aventis, was attended by eight nurses.



Course participants including Connie Henke Yarbro, Cynthia Cantril and Regina Cunningham who facilitated the course

Altogether a total of 52 nurses have participated in the workshops, coming from Australia, Brazil, China, Colombia, Germany, Gambia, Ghana, Greece, India, Indonesia, Israel, Italy, Jordan, Kazakhstan, Kyrgyzstan, Malaysia, Nigeria, Norway, Pakistan, Portugal, Thailand, Singapore, South Africa, Spain, Turkey, United Kingdom and Zambia.

The two-day workshop is designed to help nurses from around the world improve

their knowledge, skills, and understanding about breast cancer screening, early detection, treatment, support, and survivorship. Since the programme is held prior to the biannual conference of the ISNCC many of the participants have also had the opportunity to attend the conference.

The curriculum uses a train the trainer approach and includes didactic presentation,

hands-on skills demonstration, principles of advocacy and support, and teaching and learning strategies.

Past participants have had a major influence in meeting the education needs of patients and nurses in their countries.

One of the Atlanta course participants, Omolara

Fagbenle, chief nursing officer at University College Hospital, Ibadan, Nigeria said: "In Nigeria there has not been much awareness about prevention so I was particularly interested in prevention and screening. I now plan to set up a support group for breast cancer patients having seen in a presentation how good it is for these patients to discuss their experiences and their disease progression."

### A big thank you to . . .

The International Society of Nurses in Cancer Care would like to thank departing board members Carol Tishelman, Petra Fordelmann and Juliet Dreyer for their hard work and commitment.

The society appreciates the time and thought they have given to developing and strengthening the ISNCC which they have managed to do in tandem with their own busy day jobs.

We would also like to extend a warm welcome to three new additions to the ISNCC board who bring their experience and knowledge. They are Catherine Johnson, Birgitte Grube and Auxilia Chideme-Munodawafa. In fact it's a welcome back to Auxilia as she has served on the board in the past.



Pictured here together at the Atlanta conference are the five ISNCC presidents who followed on from founding president the late Bob Tiffany. Seated at the front, Vernice Ferguson, standing from left are Connie Henke Yarbro, immediate past president Sanchia Aranda, Marg Fitch and current president Greta Cummings who took over the presidency on July 1<sup>st</sup>.

# Sanchia Aranda, president 2006-10

Sanchia Aranda stood down as ISNCC president on July 1<sup>st</sup>. She looks back over four eventful years and recalls the highlights of her term in office

Professor Sanchia Aranda handed on the presidency of the ISNCC on July 1st 2010 after four successful years in office. Sanchia took over the presidency at the 14<sup>th</sup> International Conference on Cancer Nursing in Toronto in 2006, emphasising that she saw the role as an opportunity to contribute to the global development of the specialisation of cancer nursing.

Sanchia currently holds a joint appointment as Head of the Department of Nursing, University of Melbourne and Director of Cancer Nursing Research at Peter MacCallum Cancer Centre, Melbourne, Australia.

## Long-term commitment

Becoming president of the ISNCC was the culmination of a long-term commitment and relationship with the society which included serving on the ISNCC board of directors for eight years from 1992 to 2000.

Looking back over her term Sanchia said; "It has been a privilege to serve as president of ISNCC. This role brought wonderful connections to nurses around the world and offered me the opportunity to learn more about cancer control from a global perspective. Importantly, being president of ISNCC also carries with it the responsibility to ensure that the voice of nurses is heard in all corners of the global cancer community."

As ISNCC president, Sanchia worked to strengthen the role of nurses in cancer control by developing the collaborative role of the society with bodies such as the WHO and the International Union Against Cancer (UICC) of which ISNCC is a member organisation.

For example, the ISNCC established a tobacco taskforce to encourage nurses to play their part in the fight against tobacco. Sanchia also encouraged nurses to sign the UICC's World Cancer Declaration and to ensure that the potential role of nurses in meeting the targets of the declaration was identified.

Sanchia believes that the ISNCC has an important role to encourage partnerships between well-resourced and poorly-resourced countries to reduce inequities in cancer control. During her presidency the board of ISNCC removed financial barriers to low-resource societies and nurses joining the society.

The board also established a twinning



responsibility to help move the work of the society forward.

## Partnerships

The ISNCC is also working more effectively with some of its stronger members, such as the Oncology Nursing Society in the USA. Partnerships with member societies is understood as an effective means of improving benefits to nurses working in cancer care everywhere.

During her presidency the society has held two successful international conferences. The first in Singapore in 2008 was the first time the ICCN has been held in Asia. The second was held earlier this year in Atlanta, US.

Both conferences were well attended by cancer nurses from around the world and gave an opportunity to publicise the great work being carried out by individual nurses from both high resource and low resource countries. At both conferences nurses from low-resource countries were assisted in attending by travel scholarships obtained through sponsorship by the ISNCC.

programme that encourages nurses and cancer nursing societies from different countries to work together to improve cancer care.

## Firm financial base

Sanchia has guided the society through a difficult time in its history and has ensured that it now operates with a firm financial base with a professional secretariat to ensure the work of the society is consistent and effective.

Under her tenure the society has adopted a new constitution, featuring a member council that aims to engage member societies more effectively in setting the directions for the society. The new constitution also moves from a geographically appointed board to a board with clear portfolios of

She said: "Cancer is a growing world problem with more than 70% of all deaths from cancer occurring in low-resource countries. In many of these countries there is no specialist cancer nursing recognition and this creates a mandate for ISNCC to partner with national nursing organisations to promote the role of nurses in cancer prevention, early detection, treatment and support. The challenge remains to mobilise the nursing workforce to be effective contributors to cancer control efforts in all countries"

Although Sanchia's term as president has come to an end, she will continue to serve as Immediate Past President, sharing her knowledge, experience and skills in moving the society forward.

## A short history of the ISNCC

The ISNCC was founded in 1984 by a group of cancer nurses from different countries. Since its formation it has held a conference every other year in locations around the world including the UK, Singapore, Canada, Israel, Norway and Austria.

The society has developed and grown, it is a non-governmental member of the

World Health Organization, is affiliated to the International Council of Nurses and the International Union Against Cancer and a member of the Pan American Health Organization.

Now representing over 60,000 cancer nurses around the world it has kept its focus on being the international voice of cancer nursing.

# Thank you for the privilege

As my presidency of ISNCC concludes I would like to thank all of you who have offered support to me during my four year term. It has been an absolute pleasure to lead this organisation which I believe holds an important place in the totality of cancer organisations.

It is a place that is very different to your national cancer nursing society. ISNCC's role is less tangible but offers us all an opportunity to contribute to the development of cancer nursing in a global context.

The benefits for each of us are less direct and more about supporting each of our abilities to promote our specialisation and to ensure that nurses are recognised for the important work they can and do perform in cancer control.

It is easy in many countries to leave nurses out of the debates on cancer, for others to

determine the roles we can play and to speak on our behalf. In many countries nurses have little voice and our collective power is in ensuring the voice is magnified and heard.

I thank you all for the privilege of leading your organisation and to presidents of the past for establishing the foundation on which I hope I have built. I wish to offer particular thanks to the board of ISNCC who have allowed me to bring my vision to the directions of the society.

In particular I wish to thank Greta Cummings and Patsy Yates for their extraordinary contributions to our executive team and to Esther Green who has so ably led our conference team.

I would also like to thank Sarah McCarthy from Malachite Management for making my job even possible. I am not sure how past presidents coped in the role

without a Sarah to back them up and keep things moving when our day jobs take over.

I wish Greta all the best for her presidency and look forward to working under her leadership.

*Sanchia Aranda,  
ISNCC president*

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# ONS Lifetime Achievement Award

Former ISNCC president Connie Henke Yarbro has been awarded the 2010 Oncology Nursing Society (ONS) Lifetime Achievement Award.

Connie is currently the editor of *Seminars in Oncology Nursing* and an adjunct clinical associate professor at the University of Missouri-Columbia Sinclair School of Nursing.

The award recognizes her outstanding contributions as an oncology nurse researcher, mentor, and educator, as well as her service to ONS and the community at large.

In 1975, Connie co-founded ONS and has served as its president and treasurer. She realised that the society needed a way to raise funds and receive donations to expand educational opportunities and resources for



**Connie Henke Yarbro being presented with her award by ONS immediate past-president Brenda Nevidjon**

nurses and in 1981 helped found the ONS Foundation and became its first president. To date, the ONS Foundation has distributed more than \$22 million in research grants, research fellowships, academic scholarships, lectures, public education projects, career development awards, and national conference scholarships.

Connie continues to be active within the ISNCC and organised a Train the Trainer workshop at the Atlanta conference (see page one). On receiving her award she said: "This award causes me to look back with pride and satisfaction at a long journey that began 35 years ago when four of us sat down and planned the creation of the Oncology Nursing Society, which now serves more than 37,000 cancer nurses."

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# Travel scholarship awards

Travel scholarships were given to nurses from Brazil, Cameroon, Bulgaria and China for the 16<sup>th</sup> ICCN. Here three of them describe what it has meant to them

## Yan Wang

Tianjin Medical University Cancer Institute and Hospital, Tianjin, China



I am an oncology nurse, working in the department of gastroenterological cancer, Tianjin Medical University Cancer Institute and Hospital, China.

It was great to receive a travel scholarship to attend the 16<sup>th</sup> International Conference on Cancer Nursing in Atlanta. I enjoyed everything about the trip including the conference itself, making new friends, and visiting the city.

During the conference I attended a wide range of plenary and concurrent sessions as well as the member council meeting, regional meeting and the ISNCC special interest group meeting.

This was my first experience of the ISNCC and I was struck by the effort the society took to promote the spread of knowledge about advanced cancer care, especially in developing countries.

The topics discussed allowed me to gain more experience in different aspects of patient care. Coming to the conference has broadened my perspective and expanded my interest in cancer nursing, practice and nursing research. It has also deeply influenced the way I think about my work.

I have learned about the idea that we should “prevent what can be prevented, treat what can be treated, cure what can be cured and palliate whenever palliation is required” from the keynote address on *Cancer Around the World* presented by Dr Otis Brawley.

He focused on the role of tobacco in cancer incidence and the trend of cancer

development in developing countries.

He told the conference that half of all smokers today live in India and China, and that the incidence of stomach cancer in China is increasing annually. I was shocked to hear this, because in our department more and more young people are developing gastric cancer and progressing to an advanced stage.

Many of these young people are smokers. When I returned to China, I decided to produce a booklet about the dangers of smoking, and give information about healthy lifestyles.

The plenary session on *Knowledge Translation for Oncology Nursing: Moving Evidence into Practice* was presented by Lesley Degner from Canada, and Kinta Beaver from UK. They said that 30–45% of patients were not receiving evidence-based care, and 20–25% of care provided was not needed or potentially harmful.

I realised this phenomenon also existed in our hospital. This session also enlightened me in many ways as to how to improve patients’ knowledge concerning their care. In future I will pay more attention to find a way to increase their knowledge.

I visited many posters and exhibitions. I took photos of posters and gathered a lot of educational material from the exhibitions. When I got back to China, I disseminated these materials to the relevant departments. I hosted a lecture to all head nurses in our hospital to share my experience of the conference.

Then I gave a lecture to the English class at our hospital where I emphasised the importance on learning English in giving access to international nursing knowledge. If we want to align cancer nursing in China with that of other countries, learning English is the first thing we have to do. And we should be considering doing research.

In the future I intend to set up a web forum for Chinese nurses to share my experiences and discuss the information that I took from the conference. I intend to set up a team of volunteers to do translation work for nurses whose English is not good.

I hope that in the future more Chinese nurses can attend international conferences and share their experiences in the forum.

I would like to thank the ISNCC for giving me the opportunity to attend the conference and the generosity of Peter MacCallum Cancer Center for its sponsorship.

It was wonderful to meet friends from many different parts of the world. And thank you to the oncology nursing experts that I met who encouraged me to become more self-confident in my work and to overcome my nervousness about my oral presentation. I would also like to thank Winnie So and Guiyun Zhou for their day-to-day support and help during the conference.

## Daniela Simova

Bulgaria Oncology Hospital, Sofia, Bulgaria



I enjoyed all of the conference. Everything was well planned and arranged. The lectures were useful for me and I am sorry that I could not take part in all the concurrent sessions but you had to choose.

Most useful for me were lectures on survivorship and supportive care, where nurses have a main role. I liked the presentations of Joanne Itano, who spoke about alternative medicine and Won-Hee Lee, who spoke about palliative care. Also I liked the presentation by Professor Jessica Corner on how in the UK they planned survivorship in collaboration with the patient.

I also enjoyed the presentation by Winnie So, who explained how in Hong Kong they apply a programme of healthy eating and tobacco control from early childhood. Also I liked the presentation by Hiroko Komatsu entitled *Development of Education Program For Patient's Education*.

It was great that I had the chance to meet so many people from different countries with their varying kinds of education, healthcare situations and problems. In connection with this the regional meeting and the focus group that I took part in were very useful for me.

When I returned home I wrote a report about the conference and presented it to the Bulgarian Oncology Nursing Society. We

decided to establish a National Oncology Nursing Conference organised in a similar way to the ICCN

Finally I'd like to thank to Princess Margaret Hospital for supporting me and giving me the chance to go to the conference.

**Maria de Fatima  
Batalha de Menezes**  
National Cancer Institute of Brazil,  
Rio de Janeiro, Brazil



Coming to the conference allowed me to update my knowledge of oncology nursing worldwide. I was also able to compare the position of oncology nurse training in Brazil and the National Cancer Institute (INCA) with other countries.

This was particularly interesting with

respect to training incentives like scholarships, food and lodging.

I was able to contrast the situation in Brazil with that of the US and Europe. In those countries the gap between supply and demand in oncology nursing staff has made it necessary to offer nurses incentives to remain within the field of oncology

Delegates expressed great interest in the nursing involvement in the INCA Brazilian Bank of Tumors and DNA. Nurses are involved in organisation management and care.

This has contributed to the institution's success in getting patient involvement. The conference provided a great opportunity for the exchange of ideas and dissemination of the work done by the INCA oncology nurses.

By participating in the conference I was able to widen my horizons, examine my range of actions and get a worldwide overview of oncology nursing.

For me, perhaps the most important event at the conference was the meeting of the Latin American Oncology Nursing Societies, attended by 20 representatives of national oncology nursing societies and associations from eight Latin American countries.

This meeting, made possible through ISNCC, was very important for the development and establishment of goals for oncology nursing in Latin America, and allowed the consolidation of previous efforts.

For example, the decision of the Brazilian Society of Oncology Nursing,

supported by INCA, to cooperate in the training of oncology nurses in Latin America was made as a result of the meeting.

At the meeting it was decided that the book *Ações de Enfermagem para o Controle do Câncer* (Nursing Actions for Cancer Control), written by INCA care nurses, will be used as reference material in that training. The book, upon authorisation by the Brazilian Health Ministry, will be translated into Spanish and will have its contents culturally adapted.

Another outcome of the meeting was the formation of a plan for the II Latin American Oncology Nursing Congress, bringing together Central American and South American societies, to take place from April 5th to 7th 2011, in the city of Viña del Mar, in Chile.

For me, the other highlights of the conference were the presentations on:

- Cancer around the world,
- Survivorship,
- Screening, prevention and genetics,
- Models of care delivery and organisational change,
- Workforce/workplace issues,
- Strategies for success,
- Global perspectives on education.

I would like to thank Cancer Care Ontario for sponsoring me and giving me the opportunity to attend the conference. The knowledge I have gained will be directly applied to the organization of events in Brazil and to the update of emerging issues in oncology nursing, in particular survivorship of oncology patients.

## Former ISNCC president elected to MASCC board of directors

Margaret Fitch, former president of ISNCC, was recently elected to the board of directors for the Multinational Association of Supportive Care in Cancer (MASCC). She assumed her position at the annual meeting held in conjunction with the annual conference held in Vancouver, Canada, in June.

MASCC is an association open to all health care professionals who are interested in the supportive care of cancer patients and their families. Founded in 1990, it is dedicated to research and education of all aspects of supportive care for patient with cancer, regardless of the stage of the disease. In 1998, MASCC joined forces with the International Society of Oral Oncology (ISOO), an organisation that addresses complications arising in oral tissues secondary to cancer and its treatment.

Currently there are individuals from more than 60 countries across five continents who are members of MASCC. Of the members 23% are nurses.

One of the primary activities of MASCC

is an annual conference held alternately in North America and Europe. In Vancouver this year there were over 600 registrants from more than 40 countries. The next conference will be in Athens Greece, June 23–25, 2011. (See [www.mascc2011.org](http://www.mascc2011.org)).

The journal *Supportive Care in Cancer*, is the official publication of MASCC and is a benefit of membership. It is published twelve times a year and offers a wide range of topics relevant to cancer nurses. A particular focus is on current research related to symptom management.

Another key activity for MASCC is the support of more than 15 study groups for different supportive care topics; for example, fatigue, quality of life, psychosocial oncology, rehabilitation, pain mucositis, and palliative care. These groups serve as vehicles for guidelines development, education and research collaboration. They are valuable avenues for making connections with practitioners and researchers in other parts of the world.

Professor Dorothy Keefe, University of



**Margaret Fitch, former president of ISNCC**

Adelaide, Australia is the current president of MASCC. As she assumed her role, she stated that MASCC is an incredibly important organisation because, "Supportive Care makes excellent cancer care possible".

# Japan and US join for research

## A partnership between two cancer nursing societies, one from Minnesota, US and the other from Japan is developing research on survivorship

MetroMinnesotaOncologyNursingSociety (MMONS) and the Japanese Society of Cancer Nursing (JSCN) formed a friendship in 1999, with the help of the International Partnership Program of American ONS. This partnership was established because there was already a good relationship

team, the investigators propose to describe and compare knowledge, beliefs, role perception, and behaviours of oncology nurses in USA and Japan related to the follow-up care of patients currently undergoing cancer treatment.

scenarios with open-ended questions and demographic questions.

The questionnaire was developed by all of the investigators involved in this study from both organisations. It will be given to nurses recruited through the MMONS and JSCN membership.

At the time of writing, we have finished collecting the data with less than 50 to 80 nurses in each group and now are in the process of analysing the data according to the data analysis in the research proposal. We will check and compare the data between the two groups.

We plan to show the effect of the collaborative research with a presentation at an oncology nursing conference and in a paper in an oncology nursing journal.

Results may indicate there is a need for survivorship training of oncology nurses. There may be a potential to affect patient care from the information that we learn from the nurses. There may also be opportunity to translate the findings directly to health care and/or health policy.

Finally, our experience highlights some difficulties of collaborative research, for example the language barrier between English and Japanese, and communication problems when busy investigators are a long distance apart. For this reason collaborative research needs strong leaders to carry out the task required by each group.

However, in spite of the difficulties, conducting collaborative research offers participants a great opportunity to share and learn many things from each other.

*Kazuko Onishi, member of ISNCC board of directors, Professor Emeritus and Appointment, Graduate School of Medicine, Mie University, Japan*

### Benefits of international collaboration in research

- Opportunities for new partnerships
- Offers an efficiency in working
- Ability to expand and extend a research project
- Improving research quality through shared skills and reputation
- Sharing the cost of overheads
- Taking part in a shared commitment to tackle current global challenges
- Contribution to internationalisation

between MMONS and JSCN through Judi Johnson who established the “I Can Cope” patient education programme. In addition a number of Japanese oncology nurses had graduated from the school of nursing at the University of Minnesota.

One of the objectives of the partnership between the two groups is to conduct collaborative research on the subject of cancer nursing. In the past the societies have studied the differences between nurses in USA and Japan in relation to:

- rehabilitation needs following a mastectomy,
- nurses’ views about smoking.

We are now collaborating in a research project on cancer survivorship. It has been recently recognised that people are living longer following a diagnosis of cancer. However the major focus of nursing care is still on the diagnosis and treatment phases of the disease.

With increased survivorship it becomes important that nurses also focus on the potential long term effects of cancer diagnosis on psychological, socio-economic, and spiritual well-being. These are important factors affecting quality of life for people living beyond the primary treatment phase of their disease.

### Study objectives

By comparing responses to the questionnaire that was developed by the investigative

### Aims

- 1 Identify how nurses in oncology practice define “cancer survivors”.
- 2 Describe oncology nurses’ knowledge and beliefs about the needs of patients post-treatment and their perceived role and behaviour related to the care of patients regarding the post-treatment period.
- 3 Identify demographic predictors of oncology nurses knowledge, beliefs, perceived role and behaviour regarding educating patients about the post-treatment period.

In the course of these three aims the differences between the two groups of nurses (US and Japanese) will be compared.

It is hoped that this study may yield important information about the current knowledge base of oncology nurses regarding cancer survivorship and identify perceived gaps in patient education needs in this patient population. The results may inform and recommend areas that are lacking in current care of these patients.

### Data collection

Our data will be collected in the form of a structured self-administered and self-reported questionnaire to be completed by nurses working directly with cancer patients. This exploratory survey has been designed to examine nurses attitude, opinions, beliefs and knowledge concerning cancer survivorship. It includes two case



## The role of family meetings at end-of-life care in ICU

### Background

In delivering comprehensive quality palliative care, communication is central to achieving the personalised care that patients and their families desire and are entitled to. Obtaining honest, intelligible, and timely information of a loved one's prognosis remains among primary concerns of family members in the intensive care unit (ICU) (Nelson et al, 2006).

Helping families make end-of-life care decisions can be challenging for health care providers, especially in an ICU. Family meetings facilitated by palliative care teams have been recommended and found to be effective for improving support for families in these difficult situations (Nelson et al, 2006).

It has been documented that effective communication helps to improve family satisfaction, clinical decision-making, and the psychological well-being of family members (Curtis et al, 2001). Scheduled families meetings help facilitate communication between health care providers and families of patients in the ICU. A study at a community hospital also established that scheduled family meetings facilitated timely transitioning of patients to the next level of care as well as providing support for the families (Ravakhah, Chideme-Munodawafa and Nakagawa, 2010).

Communication at end of life can be improved by scheduling family meetings to allow for the emotional burden of end-of-life decision making.

Supportive responsiveness through family meetings for those who have experienced critical incidents, or who have unanswered questions or resentment about treatment may be an important consideration in alleviating later emotional burden. In addition, these families need support, comfort, proximity, and reassurance, most of which can be achieved by setting time aside to sit down and communicate with them.

Families want to feel that there is hope, and they want to know the prognosis. Unfortunately, the evidence indicates that communication with health care providers often leaves much to be desired, (Center to Advance Palliative Care).

### Observational studies

Observational studies have found that communication issues with clinicians are the number one source of complaints among families of deceased patients, with as many as 30% of family members feeling dissatisfied with communication in the ICU (Levy, 2001). Contributing factors include inadequate time spent communicating with clinicians, lack of consistent information, and

information provided by multiple health care providers. Poor communication can affect family satisfaction, clinical decision-making, and the psychological outcomes of family members. End-of-life goal setting is a key palliative care skill, typically occurring as part of a family meeting.

A study on the impact of advanced care planning on end-of-life care in elderly patients found that advanced care planning improved end-of-life care and patient and family satisfaction as well as reducing stress and depression in surviving relatives.

Elements of advance care planning include clarifying a patient understands their illness and treatment options; understanding their values, beliefs, and goals of care; and identifying their wishes. This is best achieved by scheduling time to meet with families. Often, patients become chronically/critically ill with continued respiratory failure and poor functional recovery without the health care team realising it in ICUs (Nelson et al, 2005). The lack of identifying the transition from acute to chronic critical illness often results in both the patient and family failing to recognise the potential implications for adverse outcomes (Nelson et al, 2005). This often results in the failure to institute end-of-life care.

### Huron Hospital Palliative Care

The palliative care programme was introduced to this community hospital situated in one of the economically challenged areas of Cleveland in North East Ohio, US as a result of a survey carried out by a graduate social worker student in the case management department.

The survey identified poor advanced planning, communication issues with families getting fragmented information from several health care teams, as well as frequent admissions of the elderly population who mostly used the emergency room to seek health care. As a result of these observations, a palliative care programme was initiated by April 2003 under the direction of the palliative care steering committee.

### The palliative programme

The palliative programme officially started in 2005, initially with one physician, a social worker and the coordinator, but since 2006 has expanded to include three physicians, one in charge of symptom management, the second responsible for pain management, and the third responsible for transition of patients to hospice. The Chaplain, who besides being responsible for spiritual guidance of the whole hospital, is also part of the palliative care team, and I act as palliative care coordinator, with a

background of being a registered nurse, a nurse practitioner, and PhD prepared in palliative care.

### Scheduling family meetings

The Huron Hospital Palliative Care Consult Service team functions in the acute care setting, collaborating with the primary care sector. The team identifies palliative care needs, consults on pain and symptom management, educates caregivers and professional staff as well as offering nursing assessment and interventions.

The palliative care team also participates in advance discharge planning and referrals to appropriate community resources, transitioning to hospice services at an appropriate time, as well as assisting patients and families with setting up advanced directives and providing bereavement support by collaborating with hospice organisations.

The emphasis is on quality of care through effective communication and scheduled family meetings, pain control and symptom management, and timely referrals to the next level of care. The team also provides education to patients, family members, and professional staff, and participates in assessment and interventions of patients and families to provide optimal psychosocial and spiritual support.

Apart from promoting timely access to palliative care services, the team also serves as educators and mentors for staff. Facilitation of quality of care is done through daily nursing rounds in the ICU during which screening and identification of those patients and family members needing palliative care services is undertaken.

Through scheduled family conferences, the team also facilitates patient/family understanding of diagnosis and prognosis to promote informed choices, informed decisions, and advanced planning of care to meet the multidimensional care needs caused by life-limiting illnesses.

The Palliative Care Consult Team collaborates with the primary care providers in developing a patient-centred advanced care plan. The team focuses on achieving the best possible quality of life for patients and their families. They provide relief of pain and other distressing symptoms, integrating the psychological and spiritual aspects of patient care.

The priority of the team is improving communication by scheduling family meetings. During the meetings, patients are offered support to help them live as actively as possible with the chronic illness through homecare support within the community, or through placement in various facilities.

# education and virtual cancer care

## The family meeting process

- Once a request for a consultation is received, the first thing is to communicate with the primary team regarding what they want to achieve.
  - The team should consist of the palliative care physician, the Chaplain, the palliative care coordinator who facilitates the meeting, the medical resident and the social worker and case manager where required, and some cases, the nurse taking care of the patient for update purposes.
  - The team reads through all the progress notes and examines the patient, prepares for questions from the family. Where appropriate they ask the primary team to attend the meeting.
  - Hold a pre-conference meeting to agree on the main aim of the meeting.
  - Schedule the meeting for a time that suits the family, introductions on both sides are vital to establish family spokesperson/power of attorney.
  - Avoid interruptions from pagers, telephones etc; give undivided attention to the family.
  - Do not sit behind a desk, do not stand over the family, this is disrespectful in some cultures.
  - Exercise active listening and truth telling but with empathy and reinforcement of information where necessary.
  - Avoid rushing families to make decisions — remember this is a once-in-a-lifetime decision for them that they will have to live with, but one of many for the team.
  - Reinforce the team's respect for the decision.
- Try to maximise present quality of life including the best possible pain and symptom management and support.
  - Encourage the patient and family to prepare in case treatment is not successful and the patient dies sooner than anticipated. It can be useful to say, "I'd encourage us all to hope for the best, but prepare for the worst". Introduce the topic of the hospice where indicated.
  - Emphasise the fact that the team will not abandon the patient and family even if they decide to go against what is being recommended.
  - Restate your understanding of the patient's goals and the agreed-upon next steps to meet those goals, invite and answer questions, and close the meeting.
  - Provide the family with the palliative care team's contact information in case they need a follow-up meeting.
  - Provide feedback of patient and family goals, and recommendations from the palliative care team to the primary team through complete documentation as well as verbal where indicated.
  - Debriefing is a useful step after every family meeting to assess what went well, what could have been done better, and areas of improvement, most importantly, addressing the emotional reaction and needs of the care team.

## Conclusion

Scheduled family meetings are a vital component of delivering quality end-of-life care for patients and their families, especially in

the intensive care unit. Scheduled meetings provide an opportunity to enhance the quality of care provided to palliative care patients and their families.

After each meeting, the palliative care team at Huron hospital has a chance to benefit from direct feedback.

Families have stated that they feel respected because of the time taken to sit down with them, and they feel better equipped to make end-of-life decisions after such scheduled family meetings.

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## References

- Nelson JE et al (2006). Improving comfort and communication in the ICU: a practical new tool for palliative care performance measurement and feedback. *Quality and Safety in Health Care*; 15; 264–271
- Curtis JR et al. (2001). The family conference as a focus to improve communication about end-of-life care in the intensive care unit; opportunities for improvement. *Critical Care Medicine* 29 2; 26–33
- Center to Advance Palliative Care: *Clinical Tools* Available at: <http://www.capc.org/tools-for-palliative-care-programs/clinical-tools/> Accessed June 4, 2010
- Levy MM (2001). End-of-life care in the intensive care unit; can we do better? *Critical Care Medicine* 29 2; 56–61
- Nelson JE et al (2005). When critical illness becomes chronic; informational needs of patients and families. *Journal of Critical Care*, 20 (1), 79–89
- Ravakhah K, Chideme-Munodawafa A, Nakagawa S (2010). Financial Outcomes of Palliative Care Services in an Intensive Care Unit. *Journal of Palliative Care Medicine*, 13 (1), 7

## VIRTUAL CANCER CARE

### Cancer emergencies

All nurses who work with cancer patients are aware that medical emergencies can occur. Although these are comparatively rare, we need to know how to recognise them and what to do. Some symptoms can be actively managed, whereas others involve conservative management aimed at easing distress.

It is often nurses who first spot the rapid deterioration of the patient's condition and nurses who will monitor and care for them whatever course of action is taken.

#### Patient UK

<http://www.patient.co.uk/doctor/Oncological-Emergencies.htm>

This well designed UK website specialises in giving easily understood health information from doctors to patients. This single page on cancer emergencies is what they

call a 'patient plus' article which is aimed at health professionals.

#### KMC Medical Library

<http://www.kmcmedicallibrary.org/NICCCStaffEduc/Onc%20Emerg%20Module%2008.pdf>

This 22 page downloadable pdf document from a US website is packed with useful information on a wide range of cancer emergencies and has 'nursing care priorities' section for each symptom.

#### Department of Medicine

[http://www.departmentofmedicine.com/MAS/documents/triageguide\\_emergency-guidelines.pdf](http://www.departmentofmedicine.com/MAS/documents/triageguide_emergency-guidelines.pdf)

This downloadable pdf file from a Canadian website has everything laid out in tabular format to deal with cancer emergencies.

#### Worth a look Oncoprof.net

[http://www.oncoprof.net/Generale2000/g16\\_Urgences/gb16\\_ur01.html](http://www.oncoprof.net/Generale2000/g16_Urgences/gb16_ur01.html)

This French website (the text is in English) has a whole range of information based pages on cancer treatments and prevention including emergencies.

#### AAFP

<http://www.aafp.org/afp/2006/1201/p1873.html>

For those of you who prefer a more academic approach then this online article from the American Family Physician Journal is a good place to start.

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