NSWOG
NSW oncology groups

NSW Oncology Group (NSWOG) Lung presents:

"Meeting the Needs of Lung Cancer Patients"
- Highlights from a Lung Cancer Clinical Forum

The NSW Government agency dedicated to the control and cure of cancer through prevention, detection, innovation, research and information.

NSW Government

cancer institute NSW

❖ Forum Highlights

Lung cancer remains the most common cause of cancer deaths in NSW. The Lung Cancer Clinical Forum, an initiative of NSW Oncology Group (NSWOG) Lung, was designed to identify opportunities to improve the provision of healthcare delivery to patients with lung cancer.

The Forum covered the current status of lung cancer in NSW and identified opportunities for improved care for lung cancer patients from initial presentation to diagnosis, treatment and palliation.

The event included a dramatised hypothetical utilising a professional actor as the lung cancer patient and a panel. The expertise of the panel members allowed for a range of valuable insights from general practice (GP), specialist oncology, palliative care and other allied healthcare professionals' perspectives.

A number of key themes emerged throughout these interactive sessions, including the role of the GP in the early detection of lung cancer, the need for ongoing open communication between members of the Multidisciplinary Team (MDT) and consideration of the patient's holistic needs at every stage of the healthcare delivery process.

This brochure provides a snapshot of the issues discussed at the Lung Cancer Clinical Forum. A DVD of this event is available on request (see enclosed fax form).

Panel I Members

(Above) Members: Associate Professor Dianne O'Connell (epidemiologist); Dr Simon Willcock (GP); Dr Louise Stone (GP); Dr Chris Dennis (respiratory physician); Professor Brian McCaughan (thoracic surgeon); Dr Shalini Vinod (radiation oncologist); Associate Professor Michael Boyer (medical oncologist); Ms Mary Duffy (lung cancer nurse coordinator).

Professor Stewart Dunn PhD MPH MAPS
Professor of Medical Psychology
University of Sydney Northern Clinical School

❖ Lung Cancer in NSW

Professor Jim Bishop,
Chief Cancer Officer
Cancer Institute NSW

Lung cancer is the major cause of cancer deaths in NSW. The current 5 year survival rate for non-small cell lung cancer (NSCLC) is 14.5% and 5.7% for small cell lung cancer (SCLC). These rates are similar to the US and better than the UK rates. Factors determining mortality include the extent of disease, histology, the period of diagnosis, gender and age. Opportunities exist to reduce the incidence of lung cancer and improve survival. We must aim for:

- Earlier diagnosis of more localised cancer
- Higher resection rates for operable cancers
- Appropriate referral to ensure the application of newer evidence based specific treatment as required by individual cases, and
- Implementation of better prevention approaches.

❖ Patterns of Care for Lung Cancer in NSW

Associate Professor
Dianne O'Connell,
Senior Epidemiologoist
Cancer Council NSW

The "Patterns of Care for Lung Cancer in NSW" study explored patterns of presentation, diagnosis, staging and initial treatment of lung cancer in NSW and compared these with key clinical practice indicators.

The study included 2807 eligible patients (diagnosed with lung cancer between November 2001 and December 2002) and produced the following findings:

- 66% of patients diagnosed were male
- 72% were diagnosed with NSCLC, with 54% in stage III or IV at diagnosis
- 69% were referred to a lung cancer specialist (LCS)
- Investigations at initial diagnosis included respiratory function tests (48%), radiology e.g. chest xray, CT, PET (98%), investigative procedures e.g. bronchoscopy (55%), pathology investigations e.g. biopsy (90%)
- 33% received no active treatment
- 49% received one treatment type only: radiotherapy (22%)
- Factors associated with not receiving cancer-specific therapy:
  - Female gender, >70 years old, metastatic disease, ECOG 2-4, weight loss, not seen by a LCS (or a LCS seeing <14 lung cancer patients)
- Factors associated with no referral in patients who were not treated:
  - Age at diagnosis, disease stage at diagnosis, health area

Importantly, the study found 20% of patients with stage I/II lung cancer (potentially curable) are not referred for care with curative intent and receive no active therapy.

A full report of the findings from this study is being prepared.

❖ Expert Panel Discussion

The Lung Cancer Patient: Pathways to Diagnosis

Patient Case Study: Cathy

Cathy is a 60 year old lady who enjoys general good health and an active life. She presented to her GP with a persistent cough which had not resolved following a course of antibiotics. Cathy has noticed over the past few years that, while she was never a smoker, she is getting "chestier" with age and she has been previously diagnosed with bronchitis.

She has had a 4 kg weight loss over the past 12 months (which she is happy about) and has noticed she gets tired which she attributes to regularly looking after her grandchildren. There is no other notable past medical history.

Cathy becomes increasingly anxious as the cough persists, investigations are ordered and referrals are made: "I just want to know what's wrong with me."

Symptom presentation and lung cancer diagnosis: *Panel 1 comments*

Epidemiologist:

- Of 200 general practice patients presenting with cough, approximately 1 (0.5%) will have lung cancer.

General Practitioner (GP):

- On average, a GP may see 6 patients a day presenting with a cough and/or other respiratory symptoms. The challenge is to detect the one patient every 1-2 years who has lung cancer

GPs Simon Willcock & Louise Stone

- Guidelines are needed for GPs to enable a raised index of suspicion in patients presenting with possible lung cancer
- The GP needs 3 consultations to see how symptoms evolve: the first aims to treat the cough; the second considers other factors and, where no resolution has occurred, consultation 3 prompts further investigation and referral
- In a non-smoker, like the patient in the hypothetical, any suspicion of malignancy at this stage would be of metastases from other cancers, such as breast or ovarian, rather than lung cancer.

Respiratory Physician:

- Respiratory physicians may get a referral directly from a GP or may receive referrals from other specialists if lung cancer has not yet been diagnosed
- Usually by the time symptoms appear the lung cancer is quite advanced. Our challenge is to find early stage disease before symptom presentation

Thoracic Surgeon:

- A chest xray is an inexpensive test and should be used routinely to help provide a diagnosis for persistent cough (or possible lung cancer)
- PET imaging has revolutionised the management of thoracic malignancy.
- PET imaging can determine if a malignancy is localised or spread, thus minimising unnecessary surgery.

Medical Oncologist:

- A cough which doesn't resolve should not be ignored; it requires further investigation
- To ensure less delay in diagnosis patients need to be more assertive
- GPs need further education on lung cancer and specialist doctors need to make the right decisions concerning treatment approaches.

Radiation Oncologist:

- Missed diagnosis may be due to patient and/or clinician factors – some patients don't attend their referrals and some doctors don't refer patients when they should
- Lung cancer MDTs can proactively provide further education for patients and GPs.

Lung Cancer Nurse Coordinator:

- Your first meeting with the patient is your one chance to establish trust - this should be a priority. Other important and relevant information can be covered in subsequent discussions with the patient.

The Lung Cancer Patient: Healthcare Delivery

Patient Case Study: Cathy (cont'd)

Following her diagnosis of lung cancer with metastases (adrenal gland & femur), Cathy is referred to a medical oncologist. She has a sense of urgency to start treatment as soon as possible.

Cathy is struggling with the shock of her diagnosis and the difficulty of understanding her treatment options. These are discussed with her and she is started on chemotherapy.

Ten months later, Cathy has relapsed with associated rib pain, vertebral fractures and a pleural effusion. She is once again faced with various options concerning her ongoing care, including palliation of her symptoms.

"Managing how I feel and what happens is important to me."

Panel 2 Members

Louisa Robinson (oncology ward nurse); Lissa Spencer (physiotherapist); Dr Simon Willcock (GP); Kahren White (occupational therapist); Wendy Jongs (dietitian); Laura Kirsten (clinical psychologist); Angela Kyttaridis (social worker); Debra Kennedy (carer); Claudia Giugni (palliative care nurse); Mary Duffy (lung cancer nurse coordinator); Dr Frank Brennan (palliative care clinician).

Lung cancer treatment & palliation: *Panel 2 comments*

Oncology Ward Nurse:

- Listening is key to our role, as is informing the relevant MDT members of specific patient needs to address
- Often the patient will want to talk outside of "office hours;" the oncology ward nurse is always available to provide support and reassurance.

Physiotherapist:

- Physical therapy is an important aspect of maintaining function throughout the disease. The focus should be on what the patient can do, not what they can no longer do.

GP:

- MDTs should maintain communication with the GP throughout the oncology care process, particularly when developments such as metastases and change of treatment approaches occur
- There is a whole lot of the patient that is not cancer. The GP continues to be of great value in caring for these other aspects of the patient's life.

Occupational Therapist (OT):

- An OT review aims to develop energy conservation techniques and maintain the patient's quality of life and independence.

Dietitian:

- Don't wait for weight loss before referring to a dietitian. A patient's nutritional status should be considered at every stage of the disease: pre- and post-operatively, during treatment and in the end stages of the disease
- Patients often discuss complementary medicine and dietary supplements with dietitians, so we have the opportunity to inform/educate them while still respecting their beliefs.

Clinical Psychologist:

- Patients may require referral to a psychologist at any stage of the disease; MDT members can cross refer if a need is uncovered during a consultation.

Social Worker:

- A social worker may be referred as early as diagnosis, for work and financial issues. Other areas of need are often uncovered by a social worker and referred on to other MDT members, or vice versa.

Carer:

- Patients must be given the option of what they want. Carers should be kept informed as patients are often unable to absorb the information discussed in a consultation
- Affiliation with a patient support group supplements the work of the MDT, provides the patient/carer with further information on available options and can be an outlet for patients to share experiences with non-family members.

Palliative Care Team:

- Palliative care is still perceived as "terminal care". Patients (and some healthcare professionals) need to be educated on palliation's role as symptom management and holistic support
- It is important to introduce the palliative care team to the patient before there is a crisis or significant deterioration, so they are not strangers to the patient during that time.

Lung Cancer Nurse Coordinator:

- Throughout the disease process, the patient should be the main organiser of their care, remaining in control of the options available to them
- The nurse coordinator triages the patient at initial contact, ensuring communication with and referral to the appropriate MDT members occurs. This cross-referral continues with progressive disease and the changing needs of the patient
- To reinforce the role of palliative care, use the language of palliation from early on in the disease e.g. radiation to palliate bone pain.

This brochure contains highlights from the "Lung Cancer Clinical Forum" held at the Australian Technology Park, Sydney, 2nd November 2007. The meeting was a combined initiative of Cancer Institute NSW and the NSW Oncology Group (NSWOG) Lung. This brochure intends to capture some of the key points made by the speakers and panel members during this event and as such the views expressed in this publication should be considered in this context.

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